

**A qualitative investigation of the healthcare challenges of
women with disabilities in Yogyakarta (Indonesia):
Implication for health policy**

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Florentina Dhita de LaRoche

UNIVERSITY OF CANTERBURY

School of Health Sciences

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Abstract

Women with disabilities remain a marginalized group. There are no studies currently that specifically investigate health care services as they are accessed by this group in Indonesia. For policy-makers there is, therefore, a gap in vital information. The aim of this qualitative study was to explore the experiences of nine women with disabilities aged 18 years and older in accessing healthcare services; to find out what the impact is of their disabilities on utilisation of healthcare services; and to enquire how information regarding healthcare utilization can be used to identify problems with healthcare services in Yogyakarta, Indonesia.

To capture the data, individual semi-structured interviews were conducted to elicit women's understandings of the description and construction of disabilities and healthcare services in the Yogyakarta region of Indonesia. The interviews were transcribed and analysed using Thematic Analysis. This process sought to categorise meanings underpinning participants' experiences, which were then drawn together as eight key themes that highlighted inadequate healthcare system and services, stereotyping and stigma regarding disabilities from healthcare personnel and from society, barriers and challenges leading to exclusiveness, and positive image and self-empowerment of women with disabilities.

The findings support previous studies finding that women with disabilities are still marginalized in terms of access to healthcare services. It confirmed that negative impressions within society did not impede their ability to be independent. Participants who accepted their disabilities and received family support faced the economic, productivity, economic, education, and health challenges, compensating through personal achievements. This study recognized the challenges faced by women with disabilities in accessing healthcare services and described how they manage these challenges. Government facilitation toward healthcare services for disabilities is found

to be wanting but showed some progress with the development of new programs enhanced by the meaningful involvement of disabled people's organizations.

The study concluded that women with disabilities must be actively involved in strategic efforts to mainstream people with disabilities and participate in the creation of policies. Further, the public's perceptions of disability, as a concept requires investment in public education to adjust society's behaviour toward people with disabilities. Also, the research urges the government to facilitate participation through improving access to the healthcare environment.

Definitions

Case – a person or their particular problem requiring or receiving medical or welfare attention.

Corpse – a dead body, especially of a human being rather than an animal.

Disabilities- reflecting the consequences of impairment in terms of functional performance and activity by the individual; disabilities thus represent disturbances at the level of the person.

Impairments – concerned with abnormalities of body structure and appearance and with organ or system function, resulting from any cause; in principle, impairments represent disturbances at the organ level.

Patient – a person receiving or registered to receive medical treatment.

Chapter One:

Introduction

1.1 Background

Disability, as defined by The World Health Organization's (WHO, 2014)

International Classification of Functioning, Disability and Health (ICF) is:

An umbrella term for impairments, activity limitations and participation restrictions. Disability is the interaction between individuals with a health condition (e.g. cerebral palsy, Down syndrome and depression) and personal and environmental factors (e.g. negative attitudes, inaccessible transportation and public buildings, and limited social supports). (p. 1)

An estimated 15% of the world's population (over one billion people) are living with disability and of these, 110-190 million people live with severe disabilities; 80% live in developing countries; and there is a higher representation of women with disabilities (United Nations Enable, n.d; Disabled World, n.d, WHO, 2011). WHO describes women who experience disabilities as a vulnerable group who are exposed to discrimination, violence, and abuse due to their disability.

In 2006, the United Nations (UN) passed Resolution No. A/RES/61/106 of the Convention on the Rights of Persons with Disabilities. Article 25 declares that:

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation (United Nations [UN], 2006, p.15).

The UN has pushed for equal rights and a number of countries agreeing to this charter have followed the UN recommendations. Data released on May 18, 2015, from United

Nations Enable (2014) listed 154 countries, including Indonesia that agreed to ratify the Convention on the Rights of Persons with Disability. Ratification of the UN mandate and the use of aggressive programmes not only promote the implementation of equity and access initiatives but also aim to provide improved protection of the rights of this vulnerable group.

Research undertaken in developing countries recognises that access to healthcare services is challenging even for non-disabled women due to poverty and vulnerability (Trani et al., 2011), and disabled women experience even greater challenges in accessing the health system. Commonly reported in the literature are the lacks of disabled parking areas, the absence of wheelchair accessible ramps, and in some cases, a lack of elevators. 'External factors', including poor design and inadequate examination, equipment make healthcare services inaccessible for people with limited mobility and hearing disabilities. The relative ignorance of health workers, being insufficiently educated about disability and unaware of the impact that disability has on individuals, also acts as a barrier to access (Iezzoni & O'Day, 2006; Goodman et al., 2007; Dudley & Emery, 2014; Hanson, Neuman, & Voris, 2003). Further, society's interpretation of personal limitations when an individual fails to succeed in the environment adversely influences an individual's experience of disability (Mullner, 2009).

Financial difficulties create another major impact on people with disabilities. Families with low socio-economic status cannot afford expensive healthcare services. Thus, patients try alternative treatments, such as herbal medicines, homeopathy,

naturopathy, or acupuncture (WHO, 2005; Xu et al., 2007). Lack of government support and community involvement in public health education has led to a poor understanding regarding healthy lifestyles and this results in a higher incidence of chronic diseases in countries that enjoy a higher standard of living (Spire, 2010). Additionally, stigmatisation within patriarchal systems supports the notion that disability is a punishment from God; this belief influences the community's attitudes toward disabled women, hindering progress around awareness (Agoramoorthy, 2011; Mji et al., 2009). Lack of regulatory action to protect the rights of women with disabilities, coupled with these ingrained beliefs and attitudes add to the problems caused by the disability.

Developing countries that have adopted the UN mandate share common challenges in achieving equity for their disabled populations. Emphasising rehabilitation and integrating persons with disabilities into society is a common means of attempting to help persons with disabilities to function better in the community (Valdez & Luzviminda, 1999). Legislation that enforces equal opportunity in education and employment, through accessible infrastructure, supports parity for this marginalised group and addresses the external factors previously mentioned. For greater effectiveness, strategies that tackle internal factors, e.g., empowering women through rehabilitation and social involvement, will complement measures that confront external factors (Agoramoorthy, 2011; Mji et al., 2009; Valdez & Luzviminda, 1999). Despite some development and progression of policy concerning women with disabilities, this sector still gains minimal attention from policy-makers. Disabled women remain a marginalised and oppressed population, their vulnerability

heightened by cultural constraints and exposure to violence (Mprah, Anafi, & Sekyere, 2014; MDRI-Mental Disability Rights Initiative, 2013; Agoramoorthy, 2011).

There has, however, been positive action in Indonesia, which has responded to the UN Convention on the Rights of Persons with Disabilities. Accommodating its disabled population, Indonesia had its existing legislation, Undang-Undang No. 4 from the year 1997, specifically rewritten for persons with disabilities. With respect to the updated UN resolution of 2006, Indonesia responded by signing the convention on 30 March 2007 and issued legislation, Undang-Undang No. 36 year 2009, stating that the government is obliged to look after the health of elderly and disabled people by providing an accessible health service, and other facilities, to enable this sector of the population to live independently and productively. Legislation No. 19, which was updated in 2011, was delivered as evidence of Indonesia's ratification of the UN Convention on the Rights of Persons with Disabilities.

It is imperative that the Indonesian government delivers on its commitment to equity of access to quality healthcare services despite the economic challenges, social and mobility constraints, and diverse ethnic and religious backgrounds of the nation (Agoramoorthy, 2011; Mji et al., 2009; Ahmad, Atkin, & Jones, 2002). The Indonesian Ministry of Health reported that 11% of the population, approximately 27 million people, suffer at least one moderate to severe disability (Diono, 2014). This information was obtained using the updated and adapted definition of disability (WHO, 2014), and the questionnaire on individual disability from the World Health Organization's Disability Assessment Schedule 2.0 (WHODAS 2.0). This data was

collected in 2010 with the following criteria: people who experienced mild to severe difficulties in the following categories - vision, hearing, mobility or climbing stairs, concentration, cognition, and self-care. In the 2010 report, a higher ratio of women to men with disabilities was noted; 12.8: 9.2 out of 6,174,000 people with disabilities in Indonesia (Kementrian Kesehatan, 2013). For the 2015 survey of people with disabilities, Badan Pusat Statistik (BPS - National Statistics Agency) adapted questionnaires from the Washington Group on Disabilities for use in Indonesia as a standardised measure of disability across the nation. This was expected to produce comprehensive, accurate, and consistent data from different ministries or sectors (BPS, n.d) and was to be adopted universally within the Indonesian Government.

The relationship between healthcare expenditure and health outcomes is complex. Indonesia is categorised as a 'lower-middle income' country (LMIC) (World Bank, n.d) and spends only 3.1% of its 2013 Gross Domestic Product (GDP) on publically funded healthcare services, compared to all other countries, where the overall average was 10% of GDP (World Bank, 2015). In a population of approximately 252 million, one in ten people in Indonesia, live in poverty (BPS, 2015). Indonesia currently relies on an out-of-pocket system to fund healthcare whereby individuals pay for healthcare services directly from their own funds. Thus, Indonesia's healthcare service faces a number of challenges in order to establish parity in the provision of healthcare and in order to provide equity of funding for its citizens. In out of pocket systems of funding, certain citizens forgo necessary healthcare because they lack the personal funds to pay for it, and this will undoubtedly adversely affect Indonesia's overall national health

status. However, no statistics for healthcare expenditure are available, and no evidence relating health expenditure to health outcomes.

Most Low-Middle Income Countries, including Indonesia, have ratified or signed the UN treaty in response to the Rights of Persons with Disabilities Convention and are in the process of improving conditions of treatment of, and discrimination against, persons with disabilities. Various approaches have been adopted to improve the quality of life of women with disabilities. Unfortunately, although accessible infrastructure is stipulated, building designs still fail to accommodate needs. Realistic improvements require coordination between policy-makers and architects to improve accessibility (Moyo et al., 2000; Evcil, 2009). Although the United Nations has passed a resolution declaring that persons with disabilities are to receive equal access to healthcare services, Indonesia's healthcare system has struggled to fulfil these expectations. This is of particular concern to Indonesian women, given that they experience gender-specific health issues and that disability rates among women are higher. It is important therefore, that inequities present in the healthcare system are identified in order to inform policy development that ensures women with disabilities have equal access to the healthcare.

1.2 Gender differences as a challenge in the lives of women with disabilities

Incorporating gender into research and policy-making will have far-reaching effects in building knowledge, establishing cost savings, introducing effective policies and establishing equity (Greaves et al., 1999). As pointed out by Lyons (2009), studies in health emphasise medical issues rather than individuality, diversity, or gender, resulting

in a lack of understanding of how gender impacts health and disease. Lyons (2009) suggested that a gender perspective is more compatible with the medical model of disability, but such a stance will not explain whether the social construct of femininity or the social model of disability underpins the lack of a strong voice for women. This lack of explanation is caused by the absence of analyses connecting the medical and social models to address the fact that disability influences individuals in broad and varied ways (Lyons, 2009).

Studies of gender in the health sciences may show potential for development when viewed against the medical model of health and disability. Gender views in the disability and health studies are unavoidably connected with poverty, inaccessible education, inadequate healthcare services, and inability to access health information and employment due to discrimination on the grounds of gender and disability (United Nations, 2011). Certain social dimensions, distinguished by gender, affect the lives of persons with disabilities. As described by Connell (1987), women are considered to be inferior to men in some areas of society and in some communities. Their existence is assumed to complement men's existence; therefore women must conform to the needs and desires of men. Women and men alike comply with this cultural belief, and when this societal construct is experienced in tandem with disabilities, women with disabilities become a disadvantaged group and experience unique challenges and limitations.

Studies show that women with disabilities in the Middle East are twice as likely to experience divorce, neglect, and violence as non-disabled women (Abu-Habib, 1997;

Zayatz, 1999). Case studies presented by Abu-Habib (1997) show that disability and gender are part of a tangled relationship between socio-economic and cultural factors including religious, political and public attitudes that marginalize persons with disabilities. Men with disabilities have more privileges compared to women with disabilities. From the earliest stages of life, a comparison between boys and girls with physical disabilities showed that boys would have more opportunities in life than girls (Abu-Habib, 1997). Also, girls have a higher mortality rate than boys in terms of deaths directly attributable to physical disability (Abu-Habib, 1997). This mortality is not caused by the severity of their disabilities, *per se*, but because they do not receive proper healthcare. A similar situation exists in India where more rural women experience blindness due to cataracts compared to men. This is because men are more likely to receive treatment than women (Abu-Habib, 1997; Zayatz, 1999). The same study reported that women with disabilities live longer than disabled men. However, in the early stages of having a disability, women tend to die earlier than men. Once they pass the acute medical stage the survival rate of women improves and they live longer (Abu-Habib, 1997). Therefore, the numbers of women who survive are much lower than men, although surviving women live longer. This might also indicate that the difference in longevity between genders in the disabled population may closely reflect the normal population. Further, women tend to live longer than men and because of their longer life expectancy have a greater chance of becoming disabled over time.

Disability is caused by many factors. The highest aetiologies for women are congenital conditions, disease, old age, accidents, and violence, including conflict and

war (Chitereka, 2010; Crepaldi et al., 2010). Approximately 85% arise from biological causes – through giving birth or through contracting a disease. Conversely, 57.3% of men's disabilities are due to accidents and violence alone. Women have also been shown to be at a higher risk for mental disorders, accidents, sexual abuse and age-related disabilities throughout their lives (Butler, 1990; Crepaldi et al., 2010). The WHO (n.d) discovered that the number of women with disabilities who experience psychological disabilities has been on the rise over the previous decade due to exposure to poverty, discrimination, and socio-economic disadvantage. If effective programmes are not introduced this will continue to increase the burden of morbidity for women with disabilities.

It can be concluded that women are more likely to experience disability than men. In the past, medical research assumed that women are biologically weaker, and therefore disadvantaged and more at risk of suffering chronic disease in relation to their disabilities. Biological factors are often taken as an explanation for gender differences in disability. Non-biological factors may also influence the different attitudes and behaviour of men and women regarding their own health. Women and men behave differently concerning their health condition. It seems that gender influences women to be more responsible regarding their health (Broom & Tovey, 2009; Wilkins & Savoye, 2009). As described by Lyons (2009, p. 397-398), when it comes to health behaviour, women tend to be more positive by “being concerned about health...”, “health protective behaviours”, while men are the opposite “being invulnerable, not seeking professional help, being violent and aggressive, and engaging

in risky sexual and driving behaviour”. Another influence may be society’s expectation of men, whereby males are expected to be strong and powerful (Connell, 1987).

Culturally, society views disabled women as less productive than their male counterparts and treats females differently, which positions them as an even more disadvantaged group. Men are pressed to develop skills so they can gain employment to provide an income and home despite their disabilities. This raises them to about 50 percent of the economic productivity of a non-disabled male, compared with women with disabilities who do not have similar opportunities or expectations and only attain one-third of productivity compared to non-disabled females (Lang, 2001).

1.3 Access to healthcare services and its utilisation by women with disabilities

The definition of access to healthcare services provided by Starfield (2001, p.1) is:

The perceptions and experiences of people as to their ease in reaching health services or health facilities in terms of location, time, and ease of approach.

The concept of healthcare services access is interconnected and multi-dimensional. The foregoing discussion shows no consensus on the definition of healthcare services access (Levesque, Harris, & Russell, 2013). But it was agreed that, as a concept, it connects a health system’s supply and demand and accommodates the utilisation between the users and the providers. However, quality and equality of access are not guaranteed, and is dependent on affordability, availability, accessibility, accommodation, and acceptability of the service delivery (Levesque, Harris, & Russell, 2013).

Access to healthcare services for persons with disabilities is influenced by gender. Gender inequalities occur because of self-perceived differences between the two genders, creating an imbalance of consumer power in healthcare purchasing being more detrimental to one sector (Lyons, 2009). When the services provided are given without gender consideration it creates a disadvantaged group, which receive a lower quality treatment compared to the other group (Govender and Penn-Kekana, 2008). These inequalities are also influenced by culture, society, and healthcare workers toward men and women who need healthcare services. An individual's behaviour, treatment, and healthcare access could also weaken the woman's position in receiving healthcare services (Govender & Penn-Kekana, 2008).

There are different characteristics between men and women in utilising healthcare services. One of the main characteristics that influence a woman's decision to seek health services is a biological factor; women tend to have a longer life expectancy than men (Abu-Habib, 1997). This longer life expectancy is suggested to be due to gender, even though women experience more stress and disease than men, they tend to be concerned about this and seek professional help more readily (Lyons, 2009). The combination of gender as a social factor and biological factor influences both the risk or protective behaviours. Another biological factor is explained by certain diseases that are contracted only by women or by men (e.g., prostate cancer, cervical cancer) and that require different treatments and approaches. Without a gender sensitive approach, adequate treatment will not be available from healthcare providers.

Few cross-cultural studies have been conducted to gain an understanding of the

differences between men and women with disabilities, and little is known about how gender creates differing attitudes toward disability needs. International studies have found that the provision of support needed by persons with disabilities has not been prioritized by governments (Mprah, Anafi, & Sekyere, 2014; Agoramoorthy, 2011; Ahmad, Atkin, & Jones, 2002). From the medical model's perspective, government and healthcare services share the responsibility for disability. Therefore, governments are obliged to improve the quality of their health services for people who are disabled, either in curative or rehabilitative programmes.

Inequalities exacerbate risk and obstruct understanding and management of health conditions while contributing to adverse attitudes towards health, health service utilization, and perceptions of services (Kawachi et al., 1999). For example, women with disabilities reported unsatisfactory services by doctors in primary healthcare (Fiduccia & Wolfe, 1999; Reis, 2004). With their high need for health services, frequent barriers are experienced, such as the health service refusing to provide the service, the health worker being rude and unwelcoming, a lack of preparation in managing the delivering of babies for women with disabilities, and unsafe, inhumane and painful treatment (Fiduccia & Wolfe, 1999; Reis, 2004). In certain cases, health services for women with disabilities are not considered important or taken seriously. For example, cancer-screening facilities for females are less accessible to disabled women due to systems and procedures, architectural design and attitudinal constraints.

Not only have physical barriers been recognised, such as procedural systems (e.g., insurance, transportation) and unsupportive infrastructure (parking spaces,

inaccessible location, etc.), non-physical factors such as human related constraints have also been identified, e.g., barriers arising because of poor communication, attitude, insufficient consultation, lack of empathy, lack of knowledge and lack of treatment options. For women with disabilities, this results in a higher rate of unmet health needs when compared to men (Barry et al., 2009; Bradbury-Jones et al., 2015; Popplewell, Rechel, & Abel, 2014). In discussing matters that act as barriers to health access, alongside the physical barriers, four themes have been identified: attitudes, knowledge, social norms, and control.

1.4 Significance of the study

Having no specific disability-focused legislation, regulation or policy and no evidence of previous research in this field in Indonesia, this study is intended to gather the healthcare experiences of women with disabilities as the community of interest. It is expected that the results could be used to gauge the urgency for an accommodative initial proposal on health policy. Disability is more disadvantageous for women, even though they are more interested in educating themselves about their condition and incorporating this knowledge into healthcare practices (Broom & Tovey, 2009; Wilkins & Savoye, 2009). This study uses a qualitative design to describe both the experiences and the beliefs of women with disabilities (Magilvy & Thomas, 2009; Yin, 2010). This research approach encourages investigators in the field to listen and recognise the important themes for this population, especially in daily life and does this by conducting individual semi-structured interviews with participants. For the current study, this is accomplished by conducting interviews with selected women with disabilities to

determine their unmet health needs. This research is designed to help inform policy content and development, and thereby to address the health needs of women with disabilities in Indonesia.

Furthermore, this study adds value to feminist perspectives, because focusing on women will produce richer information and specific identification of their needs and experiences. Acknowledging women's experiences and uncovering their concerns may strengthen women's positions in society and their sense of self (Worell & Remer, 2003). As active collaborators for the study, this process is expected to empower participants through them making comments, asking and answering questions and giving opinions, recognising that these women are the experts in this field (Akman et al., 2001; Hesse-Biber, 2012). They need to be confident in their ability, self-reliant, independent and have the courage to disregard the discouragement from society. Participation in the study could increase their confidence and motivation due to the sharing of their knowledge, empowerment, and social action with each other. This study is concerned about, and intends to bring out, the voices of women who are still marginalized and invisible to research, social change, and governmental regulations (Fonow & Cook, 2005; Acker, Barry, & Eseveld, 1983).

1.5 Research purpose

The study explores discrimination within the disabled community. The focus is to fill the research gap on experiences of women with disabilities in accessing healthcare services. The intent is to understand their disabilities and their interaction with physical and social environments, and the women's ability to overcome the

difficulties, to take in their experiences and grasp conditions affecting their access to healthcare services. This data will underpin proposed best practice recommendations for health and disability policy in Indonesia.

1.6 Objectives of the study

The specific objective is to explore and describe the understanding, experiences, and perceptions of women with disabilities in seeking and accessing healthcare services provided by the government, healthcare centres, and other organisations in Indonesia and how these individual impressions affect the women's use of health services.

1.7 Research questions

Therefore, the research questions to be investigated are as follows:

- 1) How do women with disabilities understand and describe their experiences of disability in their daily lives and in accessing health services?
- 2) What problems accessing health services can be identified based on the experiences of women with disabilities?
- 3) How can policies for women with disabilities be formulated to improve access to healthcare services?

1.8 Summary

This chapter has summarized the global context for women with disabilities and highlighted the current state for women with disabilities in Indonesia. Although women with disabilities are citizens with the same rights and obligations as the general population, access to the benefits conferred by these rights remains difficult. As a

marginalized and victimised group, women with disabilities experience greater difficulty in accessing their rights to usual services, such as education, health, and welfare programmes (Bird & Rieker, 2008). Current programmes do not accommodate the numbers of the disabled population and have failed to meet their needs. This study is designed to inform health professionals and public policy stakeholders and is expected to develop recommendations, which influence improvements in social welfare and health cover for disabled individuals and communities, especially for women. The challenge is to design a comprehensive health system that is most attentive to the needs of the disabled population.

1.9 Overview of the following chapters

Chapter Two – describes the overview of international studies through a range of perspectives of disability, focusing on the attitudes of women with disabilities, both toward their disability and with respect to access to health services. An initial search of international research on women with disabilities identifies data related to the attitudes of women with disabilities' toward their ability to access health services and indicates how this influences their individual experiences. A comparison of Indonesia's healthcare system to the global picture of healthcare for women with disabilities is included. There is an exploration into health service access by women with disabilities, and an analysis of the gender inequalities of women versus men with disabilities. Lastly, the chapter will give a glimpse into the effectiveness of existing policies, programmes, and projects initiated by governments to support equality and closes with a summary of the literature.

Chapter Three – provides a justification for the methodology and methods used in this study using a qualitative research design. It outlines trustworthiness criteria (credibility, conformability, transferability, and dependability) for qualitative research and the analytical approach adopted, thematic analysis. The methods section also outlines the inclusion and exclusion criteria for this study and explains recruitment, data collection, data transcription, and analysis procedures.

Chapter Four – explores the findings of the qualitative semi-structured interviews, depicting the participants' thoughts of their disabilities as this affects the management of the activities of daily living, access to social activities and health services. Before each interview commenced, an explanation was given to the participants regarding the background and purpose of the study, and the themes that were to be looked at. Quotations, notes, and summaries of the interview with participants are used as a collective voice to generate results. The conclusion highlights the remaining challenges for women with disabilities in their daily lives and for health services as a sector of government provision of services. A set of health policy recommendations are offered to emphasize the women with disabilities' own wishes in filling the gaps in services and to address their concerns and challenges. Lastly, a summary of findings is outlined.

Chapter Five – offers a discussion based on comparisons of the participants' responses and analysis of the data in light of the key points from the literature review. From there, conclusions are drawn regarding new insights and learning from this study. Finally, limitations of the current study are acknowledged, and suggestions made for further investigation.

Chapter Two:

Literature Review

Disability is a concept that encompasses health and social problems and is frequently seen through medical and social perspectives. According to Denzin and Lincoln (2011), there are difficulties defining the complexity of disability because of the disagreement over disability as a concept. The shifting perspectives from medically oriented points of view to environment oriented opinions have been generated, in-part, by the deprivation and oppression experienced by persons with disabilities. The disability revolutionary view, to resist oppression, proposed a new perspective that is beyond disability. The new concept proposes that disability is not only a medical concern; but also a societal and environmental concern. These perspectives need to be integrated to support persons with disabilities against unnecessary disablement. The WHO classification of disability includes three key factors: impairment, disability, and handicap (WHO, 1980; Donovan, 2010). Underlying the classification is the concept of an individual's ability to participate in social relationships, the environment and in activities, which may be affected to varying degrees as a result of functional differences. Those three components are derived from various perspectives of disability such as the medical and social models.

2.1 Medical model

The medical model originated from the work of the WHO through the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) (WHO,

1980). It provided a perspective that portrays disability as a disease or illness, even though it may not be curable, and hinges on the individual's physical condition. The International Classification of Impairments, Disabilities, and Handicaps (ICIDH) views disablement as a result of diseases or illnesses that require interventions. It refers to 'persons with disabilities', which derives from the idea that at the core of disability is a disablement that can be eliminated with proper medical intervention (Oliver, 1990). It suggested that medical research and experimental interventions will work best to normalise persons with disabilities. Cure and/or rehabilitation is undertaken to assist and manage the illness and its disability. Thus, the expected result is that the intervention could fix people with disabilities so they can function normally. Normal function is the focus.

In agreement with the ICIDH definition of disabilities, many researchers have focused heavily on the medical perspective for the core concept of disability by concentrating on diagnoses, treatments, and health policies (Shakespeare & Watson, 2001; Schaaf, 2011; De Campos Velho Martel, 2011). Through these studies, it was reported that many governmental agencies supported the medical model. This support is visible through the implementation of disability programs under the Ministry of Health and the Ministry of Social Welfare of the countries studied (Rothman, 2010; Garden, 2010; Oliver, 1996; Gatjens, 2011). On-going disability programs by governments are implemented, focusing on the medical model combined with the charity framework, which distinguishes the physical condition via a diagnosis, e.g., impairment, and the impact of impairment on function. In reality, this trend led to the

recognition that further understanding of disability is required in order to achieve desired outcomes. Factors related to disability, such as age, gender, and sociocultural norms (WHO, 1980) are not identified through this approach. Thus, it is clear that the medical model or framework is limited by regarding disability as a medical issue, only to be viewed within the realms of healthcare.

The challenges of the implementation of policy based on the medical model in Latin America were pointed out by Gatjens (2011). According to his study and analysis, the lead governmental agency for disability was the Ministry of Health. It was responsible for the implementation and monitoring of the Convention on the Rights of Persons with Disabilities programs in Latin American countries. The Ministry of Health was considered to have extensive knowledge of medical issues; therefore, people with disabilities having medical problems required management by the Ministry of Health (Gatjens, 2011). In his review, Gatjens (2011) suggested that disability programs and interventions by the Ministry of Health had not provided satisfactory outcomes and failed to seek inter-agency collaboration, nor integration through the involvement of persons with disabilities and were, therefore, unable to successfully convey and implement the programs' objectives.

There were no findings in examining the Indonesian government's understanding of disability in the available literature. However, a review of government documents indicates that Indonesia's implementation of programs based on the medical model for disability is slightly different from Gatjens' (2011) findings in Latin America. In Indonesia, the leading role and responsibility of implementing disability programs do

not lie solely with the Ministry of Health. The inter-agency's roles and responsibilities are unclear and overlapping between the Ministry of Health and the Ministry of Social Welfare, and/or other agencies (Kementerian Kesehatan, n.d). Rather than an integrated program, the Indonesian government believes that welfare programs (e.g., rehabilitation, fund aid) should be managed by the Ministry of Social Welfare, while health-related programs (e.g., treatment, therapy) by the Ministry of Health (Kementerian Kesehatan, n.d). This overlapping coordination is as a result of the adoption and utilisation of different guides regarding management of disability. It is also due to the narrow definition and limited understanding of disability models underlying this approach (Combrinck & Reenen, 2012; Pattiro, 2016; Saltes, 2013). This agrees with the literature criticising the medical model (Gatjens, 2011; Combrinck & Reenen, 2012). Studies such as this recommend integrated programs; coordination of inter-related agencies; and advisory and supervisory functions undertaken by the disability community itself.

In more recent years, the medical model has been subject to criticism because of the unclear framework for determining disablement. It did not look at comprehensive factors beyond the individual with disablement. It failed to integrate social, cultural, economic, and environmental factors into its framework. The perspective of disability as an illness requiring only medical intervention to be normal no longer fits with the experiences of the person with a disability. Rather than being significantly helpful, medical intervention could conversely further constrain the individual because there were no beneficial functional effects of intervention according to that model. Even

though medical intervention could overcome abnormality of function, there are other solutions that deliver the same outcome. When medical treatment failed to improve the function of a person with disabilities, other perspectives were needed to uncover the potential to live and avoid medically derived oppressions. Green, Carrillo, & Betancourt (2002, p.143) stated: “healing tools and instruments of science are blunt and ineffective when used blindly in ignorance of the meaning and context of a patient’s illness”. They suggested that the health professional needed to add skills to reach out and communicate with patients from a perspective beyond the health sectors’ constructs.

2.1.1 Medical model and women with disabilities

Within the medical model, the definition of normal is considered important in setting a standard for comparison, however, it is difficult to establish what normal is for people with disability. According to Davis (2013), normal could be defined as something that does not deviate from what is common. Disability is viewed as inferior when compared to a ‘perfect body’ that enjoys medical fitness. It can be argued that the medical perspective toward the body as normal or impaired is rooted in a social construction i.e., the patriarchal view covertly expressed within the medical field itself. Those who do not have this commonality of presentation, therefore, has aspects of themselves that need to be corrected and is considered abnormal. This standard of a normal versus an abnormal body was constructed and established by representatives of the normal group, as the dominant sector, and subsequently disseminates this biased concept of normal through the media. This view sees disability as an abnormality that needs to be hidden and/or corrected.

Disability in the medical norm measured by the medical expertise according to what is the normal standard. The problem for this measurement is when the disability is not visible. Invisible disabilities defined as an impairment that cannot be recognize through the appearance, but could hinder a person's activities due to its negative effect to the body (Ring Jacobsson, 2011; Taylor, 2005). Some examples of invisible disabilities include: chronic pain/fatigue/dizziness, mental illness, coeliac disease, auto-immune disease, and learning disabilities (Disabled world, 2015). People with invisible disabilities experience greater challenges compared to people with visible disabilities. The challenges faced particularly is in justifying the impairment, further with the discrimination received from the healthcare worker due to the unseen impairment hard to measure and lack of knowledge of it (Ring Jacobsson, 2011; Taylor, 2005). With that reasons, women with invisible disabilities are prone to greater discrimination and marginalization from the healthcare professional, the society, and the disability community.

Studies of women with invisible disabilities are still limited. Few of existing studies investigated the experiences of women with invisible disabilities. It recognized that invisible disabilities were not handled properly by healthcare services compared to the visible disabilities (Dale Stone, 2005; Taylor, 2005). Dale Stone's (2005) study with 22 women with post-stroke and its sequels have similar conclusion with a study from Taylor (2005) on 47 people (45 females, 2 male) with chronic fatigue syndromes. Both of the studies suggested that the participants received a little of acknowledgement for their invisible disabilities from the disability community and the healthcare professionals.

Also they experienced difficulties in legitimize the invisible body symptoms as part of disabilities. Between 10-54 percent of healthcare professionals would not recognize or choose to ignore chronic fatigue syndromes as a medical problem, lead to inappropriate expertise and treatment planning (Taylor, 2005). The women in both studies opine it is easier to be accepted when someone have visible disabilities rather than the hidden one. This notion is supported by the argument that disability is more associated with body parts as a visible form of physical appearance (Thomas, 2001; Peuravaara, 2013; Kirch, 2008).

2.2 Social model

An alternative interpretation of disability is the social model. Supporters of this paradigm are Holmes and Dea (2012), who considered disability as natural and most likely to be encountered in everyday life, explaining that any individual is confronted with different hurdles related to disability, weakness, and dependence. This natural state encourages humans to build social relationships with one another. Thus, the social model sees disability as simply an extreme grouping within the range of normal communities, whose members are labelled as the weakest, most flawed, and most dependent. Thus, weakness, disability, and dependence are not personal characteristics of an individual entity – that of an idealized, rationalized, and atomized body per the medical model – rather this view of disability depends on the social attitudes and behaviour of the community toward the disabled person, as a sector within their own community.

The position of Holmes and Dea (2011) was aligned with the Union of the

Physically Impaired Against Segregation (UPIAS). Over time the ICIDH classification and implementation were considered narrow by the UPIAS in the United Kingdom (UPIAS, 1976). The Union of the Physically Impaired Against Segregation (UPIAS) claimed the social model is more appropriate, defining the differences between impairment and disability. It argues that disability was seen as a limitation to function because of external factors, acting on the person as barriers, prevented a person from undertaking certain functions and reflected on how a person interacts with, and is valued by, society. It also believes that isolation, rejection, and oppression arising from disability underpinned the negative impression towards persons with disabilities (UPIAS, 1976). This view countered the limitations of the ICIDH classification, which heavily relied on the medical model (Siminski, 2003; Forhan, 2009). This movement by the UPIAS influenced the reformulation of the ICIDH definition, which was then developed and improved into the International Classification of Functioning, Disability and Health (ICF) in 2001 (WHO, n.d). Even though the ICF classification is still based on health parameters, it has a broader context beyond the medical paradigm and no longer sees disability simply as a consequence of disease. Disability is now seen not only as a medical issue but also as an interaction between a person and his or her environment, and the consequences of this interaction on a person's function (UPIAS, 1976; WHO, n.d).

In comparison to the medical model, the social model considers disability to be a social issue arising out of society's attitudes and the environment. Within this model, a person ought not to be labelled as being or having a disability, until it is proven that

he/she is prevented from doing something (McGuire, 2012). For example, a study on autism by McGuire (2012) found that the definition of autism is a social construction as it changes according to “times”, “spaces”, “diagnostic criteria”, “attitudes”, and so on. These factors are the barriers standing between persons with autism and the environment. When the barriers are removed, the person with autism receives the opportunities to improve their lives and succeed, it means autism is non-existent. This concept is also applicable to disability when persons with disabilities are facilitated to participate and succeed; it means that this disability is not present.

This concept is supported and elaborated on by Brownlee and Cureton (2009) and Rothman (2010) who agree that the environment contributes to the creation of social and cultural obstacles for persons with disabilities. Rothman’s (2010) assessment of the implementation programmes stress the limitations experienced by individuals and makes efforts to accommodate persons who are disabled. For instance, if an individual has an amputated leg, this is not stigmatized, but rather accommodated with the right devices to support mobility, and via accessible building facilities such as ramps. Thus, the environment (social and physical) is modified so that an individual can function normally. Armstrong, Armstrong & Barton (2000) added that such socially disabled individuals are often hidden from the public by their families and consequently experience impeded access to schools, health, and social opportunity. This subject was identified by Gupta (2012), who noted that the disabled group is the most disadvantaged regarding employment. It can be concluded that they are the most unwanted and so will be labelled as a burden, raising a problem for persons with

disabilities wherever they are in society. Despite the obvious limitations of the above position, it can be deduced from a critical analysis of the literature that the social model is seen as a more valid perspective than the medical model, even without the complication of disability (Moore, 2002; Munyi, 2012).

Along similar lines, Munyi (2012) conducted a further review of the literature on disability between years 1937 to 2002 and found societal attitudes are one of the problems raised by persons with disabilities. Attitudes are influenced by the local culture and societal behaviours. He suggested that a reduction in prejudice and discrimination toward the disabled is best achieved through a coordinated program between government and disability organisations. That study added that, for such a programme to be successful, the medicalization, conformity, attitudes, and treatment of persons with disabilities must be recognised. Therefore, this model notes that society must participate in the challenges to eliminating obstacles for persons who are disabled, in order to enable them to access the environment and be independent.

It can be concluded that the social model, rooted in the human rights movement, is mainly constructed to empower the individual. This proposition implies that every person has fundamental rights that must be facilitated by the government (Combrinck & Reenen, 2012). Shakespeare and Watson (2001) stress one key fact of the social model – this perspective recognizes that the solution lies in social deconstruction or total societal transformation. This strategy seeks to remedy through the removal of barriers being experienced by disabled persons, whether such barriers are physical or attitudinal.

The literature has emphasized that both state and society need to be aware of the significant influence of existing social constructions and the negative effects they can have on the standing of the person with disabilities, in society (Barnes & Mercer, 2010; Davis, 2013). Schaaf (2011) built on these arguments by stating that the social perspectives see disability as an issue that arises from social pressures. A distinction has therefore been made between impairment and disability. Disability is an incapacity construed by social constraints, whereas impairment is a physical or mental dysfunction or disadvantage (Schaaf, 2011). However, the social model's attention to physical and environment barriers has often failed to accommodate social factors beyond disabilities, such as gender, ethnicity, and social status. It also neglected the subjective experiences of an individual from a medical point of view (Shakespeare & Watson, 2001). Despite the growing support for the social model, disability still does require medical treatment to help manage it.

It needs to be highlighted that perspectives on disability are not limited only to medical and social perspectives. Each of the models has been developed with variations, contributing to the understanding of the complexity of disability. Other perspectives such as the charity model, the economic model, the empowerment model, the religious model, the social adapted model, and the comprehensive bio-psychosocial model (WHO, 2005) are employed according to need. Based on existing regulation and programs, the Indonesian policy-maker still adheres to the medical and charity model, reflected in their decision that created a hierarchical social construction composed of the donor and the recipient groups. The donor group is the giver, and the beneficiary is

the person with disabilities. This construction is believed to be the best way to aid the unfortunate situation of disability and assist to compensate for the imperfection.

The attitudinal and environmental barriers related to disability create social exclusion and disadvantages. The social model offers a positive breakthrough through its attention to the social and environmental barriers achieving inclusion of people with disabilities in the process. Thus, the social model presumes to remove the barriers caused by disability and to help the person with disabilities to have a normal life. These deliberations will be useful when considering how expressions of the social model are taken into account when defining an accommodating and responsive health policy.

Disability is a compounding effect produced by a combination of the impairment and environment. And if the two contributor factors are eliminated, it would not mean disability would be resolved. Outside of impairment and disability is where the solution lies. Factors such as societal and cultural hold a broad spectrum of policy and widely differing opinions on the definitions of barriers for persons with disabilities, and the implications of those barriers on individuals. Both the social and medical models have been relevant and convincing during their eras, but neither can accommodate the complexity of, and the wide-range of, problems experienced within disability.

To summarize; **Table 1** provides a comparison between the two key perspectives on disability as captured in the literature described above.

Table 1. Comparison of Medical Model and Social Model of Disability

Distinctions	Medical Model	Social Model	References
Ontology	Rationalism: There is a perfect form of the human body	Empiricism: there is no perfect human body	Shakespeare and Watson, 2001
Source of disabilities	Deficiencies in the body	Social pressure	Shakespeare and Watson, 2001
Concept	Impairment is disability	Impairment is different to disability	Schaaf, 2011
Solutions	Medical treatment or rehabilitation; outcome measurement (evidence, treatment, and recuperation)	Total transformation of society's attitude; moral and cultural understanding	De Campos Velho Martel, 2011
Descriptors	Persons with disabilities (PWDs)	Disabled by unaccommodating environment	Shakespeare, 2002
Treatment	Patient	Social welfare intervention, beneficiary	Gatjens, 2011
Government responsibility	Ministry of Health	Ministry of Social Affairs	Gatjens, 2011
Political Perspective	Welfare, paternalistic: the individual is the object of legal intervention	Human rights and society: the individual is an agent who has rights	Combrinck and Reenen, 2012

Source: Shakespeare and Watson (2001), Schaaf (2011), De Campos Velho Martel (2011), Shakespeare (2002), Gatjens (2011), Combrinck and Reenen (2012).

2.2.1 Social model and women with disabilities

The social model proposes that social construction is the cause of the marginalisation and oppression of women with disabilities. They are facing negative attitudes in the form of segregation from society, stigmatisation, discrimination, and punishment depending on the norms, cultures, and beliefs of the society. This behaviour, coming from private and public domains, relates to social role theory that expounds this point of view and the consequent abuses. Additionally, in developing countries, the right support from respective government agencies is still difficult to find (WHO, 2005). The combination of their vulnerable position as women and the stigma of disabilities, plus the lack of support from government causes women with disabilities to

be unheard and marginalized (Hladki, 2008; Begum, 1992; Puri, Misra, & Hawkes, 2015).

The social model through a feminist perspective recognizes disablement and gender oppression toward women with disabilities is a part of common practice from a healthcare professional (Thomas, 2001; Kirch, 2008). In the medical field, social construction sees the able-body as normal, thus, when healthcare professional faces women with disabilities as patients, their attitude in treating the patients' influenced by disabilities or gender factors, rather than a single entity (Thomas, 2001; Peuravaara, 2013). Lack of knowledge from the health care worker could fail the problems identification, as medical and social issues need different approaches.

Hladki (2008) suggested that in order to be heard, women with disabilities have an obligation to act. Hladki (2008) stated that disabled peoples themselves are responsible for correcting discrimination through appropriate attitudes in order to overcome their situation and in order to achieve improved conditions - that the solution is within the power of the individual with the disability and how they interact with society. On the other hand, there is an alternative proposition that disability is a social construction. Societal constructs are expressed through social control, resulting in women with disabilities being marginalized, and denied expression. Therefore, the view that the responsibility is in the hands of individuals with disabilities is untenable. Society and culture itself must change.

There is also a debate about whether the social construction of women and disability can be separated. Society sees women and disability as two different matters, each of which requires special handling in an attempt to escape from under the heavy

hand of discrimination. As Groce (1997) observed, not many studies have been conducted on the life of women with disabilities, so little is understood of the difficulties experienced or the factors involved. Begum (1992) has proposed a related line of thought within the development of divisive identities within the broader category of disability. Disabilities are seen as integral to women with disabilities; the woman and her disabilities are inseparable. Thus entwined, Begum (1992) purported that problems need to be solved through a comprehensive focus on the everyday realities faced by women with disabilities. Feminist scholars propose to raise the dignity of women with disabilities in society by ending discrimination; raising public awareness of injustices, and reshaping and restructuring society.

Discrimination, faced by women with disabilities, informs an important component of health policy. Angelides (2012) defines discrimination as all acts that distinguish between individuals or groups that benefit one party while harming the other party. Based on this definition, if an action helps persons with disabilities to be able to walk while non-disabled persons do not have the same assistance, this is not discriminatory but enabling. When such help assists persons with disabilities to participate in work or other activities, this support also benefits the non-disabled population to join the participation. Such interventions benefit both parties. Morris (1989) noted that discrimination towards women with disabilities may arise from judgments regarding their physical appearance, which immediately renders an opinion based on social conformity. Without public acceptance, the disabled population will not be able to voice their opinions. And without the disabled population expressing

their opinions, people will not understand the inside world of women with disabilities. Moreover, because disability is very diverse, people with disabilities can be considered as separate groups and their collective voice further weakened.

2.2.2 Embodiment influences toward women with disabilities

An embodiment could be defined as a relationship between the individual's bodies with the changes that happened to it (Braithwaite & Thompson, 1999). The human body, to society, is seen in several ways. According to Grosz (in Erickson, 2007), a body has three functions; as an object, as a tool, and as a medium. What this means is that a body could be used for science; to achieve something, and as a means to communicate. Erickson (2007) strongly criticized this categorization because a body could be thus interpreted as a subject that needs to be corrected and controlled, therefore people will try to pursue "perfection", a concept that is an illusion. Another challenging theory that was put forward by feminists discussing disability is an embodiment concept regarding private and public duality.

MacNevin (2003) added that social factors, related to the embodiment, influence women's social roles. Embodiment, from medical thought, views the body not only as an object but also as an identity. As an identity, it, therefore incorporates elements of sociological thought. In line with this, Thomas-MacLean and Miedema (2012) discussed embodiment, a concept according to which, a body can be studied as an individual identity, as a political and social entity, and as a tool, e.g., for violence. The concept of embodiment highlights human health and disability across a number of functions. The embodiment is dialectic of various dimensions of experience, especially

concerning a person's physical body in relation to the sociological body (Thomas-MacLean & Miedema, 2012). It could be concluded that human beings not only use their bodies to perform basic functions but also for advanced social functions such as demonstrating social status or sporting prowess. Humans may even modify the body to enhance these advanced functions through plastic surgery or other forms of medicalization.

Ghai (2003) and Rogers and Rogers (2010) observed that the physical differences of women groups with and without disabilities create the thought that women with disabilities are unable to care for themselves performing daily activities, therefore require some form of assistance. MacNevin (2003) showed that this psychological dilemma faced by adult women is associated with problems of self-respect. Not only does embodiment pose challenges to the woman with disability but gender stereotyping influences societal expectations as well.

In the non-disabled group, public and private dimensions of the body are obvious and are specified by various types of clothing and rituals related to the transition between private and public areas of the body. For women with disabilities, the problem becomes complicated because of the need for personal care, especially if the public and private domain includes what may be touched and not touched by others and when and how this may occur. Erickson (2007) a paralyzed woman tells of her experience. She had to rely on assistance to meet most of her needs – both in her private and public areas – preparing meals, dressing, bathing, sleeping, walking, bowel movements, etc. From the public-private duality perspective, the disabled individual

does not have privacy parameters at all. Indeed when attempting to provide privacy it may place the woman with disability at risk of harm. For example, women with disabilities requiring rehabilitation may be provided a private room, but this practice can be potentially life threatening in a busy ward.

Sociological perspectives on the body consider that sickness and disability lead to devaluing of the human body, especially with respect to women. This devaluation is accompanied by attitudes and discriminatory behaviours that seek to keep the sick body or disability hidden from the public and the person is therefore, neglected. Social role theory according to Eagly (1987) states that a person's behaviour is shaped by social expectations. The most obvious social expectation is in respect of gender. Women are expected to be housewives and good wives while the men are seen as the breadwinners. However, this expectation and generalisation of a woman's role is constructed through a male perspective. This image was shifted by the women's movement in 1960's when women were allowed to voice their opinion and had equal rights with men, rather than as a housekeeper. When these gender roles cannot be fulfilled, the community applies social pressures causing an individual with disability stress. Unmitigated stress will result in diminished life satisfaction. As a result, women with disabilities could experience decreased life satisfaction not because they have a disability, but because of social roles that have not been satisfied (Eagly, 1987). The social role of women with disabilities is unclear due to this disadvantaged position on two differentiated levels – as women and as people with a disability. Having a disability can impact a woman's ability to fulfil their expected gender roles. A woman's role is

determined by society through physical perfection, being a wife and mother, and her ability to complete domestic tasks. Disability may prevent them from fulfilling this role, especially when society is not willing to give them the opportunities to prove themselves. It has been suggested that women stigmatized by society as incapable of fulfilling the role of a mother and spouse and are seen as weak and dependent on others even for their social lives. This may lead to frustration and depression in women with disabilities (Ghosh, 2010; Kolb, 1981).

2.3 'Productivity' of women with disabilities

In patriarchal communities, women are primarily the caregivers of children and the family. With a disability, this key female role is often considered unattainable (Mental Disability Rights Initiative [MDRI] Serbia, 2013). Women with disabilities have reported the importance of caregiving and how government cannot cater to this need (Combrinck & Reenen, 2012). Perceived failure in core roles and subsequent rejection of the women with disabilities leads to prejudice and stigma. The women are cast out from home and family and, in extreme cases, are at risk of becoming human trafficking victims (MDRI Serbia, 2013; International Network of Women with Disabilities [INWWD], 2010). This study in 2010 showed that women with disabilities experienced emotional, sexual, and/or physical abuse from family members, caregivers, healthcare providers, and strangers (INWWD, 2010). The effect of prejudice and stigmatization stems from the fact that women with disabilities are treated as objects of abuse be it emotional, sexual, or physical (Human Rights Watch, 2010; Kothari, 2005).

Further, violence is perpetuated and tolerated because communities view disabled persons as “not completely human and of less value” (Iglesias, 2004, as cited in INWWD, 2010, p. 6). Thus, being seen as not fully human, the “absence of representations of their identity favours the perception that one can abuse them without remorse or conscience” (Iglesias, 2004, as cited in INWWD, 2010, p. 6). Therefore, based on the stigma experienced by women with disabilities, it is vital for the current research to identify how health policy has influenced the attitude of the Indonesian populace toward disability in women. A study by Lanoix (2013) purported that a government should utilise such considerations as the examination measurement. The study categorised society into three groupings of productivity: pre-productive age, productive age, and post-productive. The emphasis is on the childbearing age because it includes a sub-group of individuals who are not productive within society: this subset includes productive-age individuals with disabilities. These people receive social assistance, training, and consultancy programs geared toward their independence, in order for them to become productive. Performance statistics reported to the government evaluate this empowerment method (Quinlan et al., 2009). Lanoix’s (2013) study highlighted this matter regarding the vulnerable people group to the French government. It critiqued the existing program, which addresses the productivity of vulnerable people (elderly and disabled) to be able to contribute to society, therefore having long-term benefits for the recipient. Skipton’s (1997) article, on the other hand, comprehensively analysed the policies and strategy of the Canadian government from the viewpoint of women with disabilities in the workforce. Women with disabilities

were categorised by their employment status: 'unable to work', 'looking for work' and those who 'work a full-time job'. She claimed that the health and finances of women with disabilities were directly affected by the availability of work they can participate in. Therefore, she encouraged women with disabilities to fight for their rights (Skipton, 1997).

2.4 Daily challenges and discrimination faced by women with disabilities in developing countries

In certain societies, women tend to have lower access to resources because of the lower distribution in income, nutrition, and social support within the household compared to men. A woman is more likely to have a disability during their lifetime because women tend to live longer than men and being female is a contributing factor to limited access to healthcare, either for preventive services or as a treatment (WHO, 2005; Emmett & Alant, 2006). Three quarters of all women with disabilities in the world are located in developing countries (Human Rights Watch, 2006), where they experience greater disadvantages. Further, Emmett and Alant (2006) claimed that even though women with disabilities are located in developing countries, there was no accurate evidence that there is a higher number of women with disabilities compared to men. It suggested two possible reasons, the inaccuracy of the recorded statistics and the premature death of the women due to limited access to healthcare services.

Low-income countries equate to low wages and poverty in the population (UNESCAP, 2015). Women with disabilities from low-income countries who fall into poverty experience higher economic challenges and are more often exposed to a cycle

of poverty compared to able women and men. When this fact is added to the lack of opportunities for education, employment, and healthcare it results in the circle of poverty and disability being hard to break. Disability either as a cause, or a result, will confine the individual to poverty (Emmet & Alant, 2006; Lustig & Strauser, 2004; Groce, London, & Stein, 2014). This is connected with socio-demographic, systemic and psychosocial constraints such as knowledge, attitudes, and lifestyles of the LMIC countries. Gender status has previously been discussed as a challenge faced by women with disabilities. Thus, the combination of gender with social, cultural, structural, and political influences makes them less valued than men. Negative perceptions of disabled women position them as subordinate and therefore they are denied opportunities and access within economics, social inclusion, human rights, and discrimination with few prospects (Morris, 1989). By reducing marginalisation and improving employment opportunities it is expected that women with disability will be more able to escape the poverty trap. The marginalisation of women with disabilities occurs in broad sectors, i.e., health, employment, education, financial, social, etc. It is a combination of inter-related factors that excludes women and discriminates against them causing limited participation and access. Exclusion through these means has led to this group being "invisible" within society. Inaccessible resources of society will push them to further untenable outcomes: impairment, inequality, and marginalisation.

Researchers that have studied barriers to employment for women with disabilities are still few in number (Yeo & Moore, 2003; Mitra & Sambamoorthi, 2009). Women with disabilities as workers are depicted negatively. They are considered to be

incompetent, unhealthy, disadvantaging, and not beneficial for the company.

Companies avoid hiring them (Yeo & Moore, 2003; Mitra & Sambamoorthi, 2009; Morris, 1989; Jones & Latreille, 2010). As reported by the United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP, 2015), employment numbers for women with disabilities are much lower than men with disability in low-income countries such as Sri Lanka, Thailand, Turkey, Iran, India, Cambodia, and Guam, with ranges between -4.9% to 32% differences lower employment rates in women with disability compared to their male counterparts. The reasons as analysed by Emmet and Alant (2006) were the multifactorial disadvantages faced by women with disabilities. They described the women's challenges between developing and developed countries to be similar: inequalities for women with disabilities in finances, opportunities (e.g., in education, healthcare, information, transportation, facility), employment, and gender roles. The differences stem from prejudice and cultural aspects as the more influential factors in how society treats women with disabilities as individuals. One suggestion that was stressed in that study was to approach disabilities through an integration of related programs and sectors, rather than an individual approach. A number of studies also reported that women with disabilities suffer greater prejudice compared to men with disabilities and compared to able-women, and this prejudice especially comes from men (Robinson, Martin & Thompson, 2007; DePaulo et al., 1996; Pintabona, 2009; Kolb, 1981). Moreover, prejudice within the social and cultural environment highlights the insignificant and ignored voices/perspectives of the women due to being labelled incompetent by society (Pintabona, 2009).

Even so, the self-perception of women with disabilities leads to attitudes that could further weaken their position within society. When it comes to employment, women with disabilities tend to have more negative experiences than able-bodied women. They have difficulty obtaining employment or are employed with low income, a fact confirmed by the UNESCAP (2015) report. It stated that in developing countries, the types of job offers women with disabilities gain are labour intensive jobs, such as sewing, assembling, or knitting which are paid low wages. Disabilities and lack of education make women with disabilities to be considered undesirable employees. They tend to have lower employment opportunities and work history compared to able-bodied women and men and the outcome is a low income (Mitra, Posarac & Vick, 2011; Mitra & Sambamoorthi, 2009). The challenge not only comes from being disabled but is combined with the effects of gender bias in society and the lack of opportunity. Therefore women with disabilities end up being self-employed or in low-skilled, low-paying labour jobs. Additionally, intensive labour work is quite challenging for a person with a physical impairment and low wages fail to support living costs and extra expenses needed for device purchase, assistance, and healthcare for those with the disability. This is a troubling scenario and significantly affects financial well-being when the out-of-pocket healthcare payment is the common practice.

Children with disability often lack opportunity for education because parents refuse to send disabled children to school because they cannot afford it and this, in turn, contributes to their poverty as adults (Lustig and Strauser, 2004). The cost of special schools is higher than public schools, but they do not necessarily have accommodating

infrastructures that would be beneficial for the family (Filmer, 2008). With a lack of education, the chain of opportunities for attaining a better job and better income is gone. Thus, with a disability, the poverty cycle continues.

The right kind of infrastructure is important for disabled people to realise their potential. Whilst they will be adept to adjust to the environment, access to information, transportation, and facilities are daily challenges. Drainoni et al. (2006) further noted that without assistance or a mechanism to overcome physical barriers, it is likely an individual will be discouraged to reach the service needed and this leaves them feeling excluded from their community. Discouragement is evidenced by people with disabilities cancelling trips due to infrastructure obstacles. In rural areas where the infrastructure is not as supportive as in urban areas, persons with disabilities find it inconvenient when there are no paths or ramps and prefer to avoid undertaking such trips. The isolation arising from being denied access to persons with disabilities needs to be eliminated to accommodate the interaction between impaired persons and the environment (Loeb et al., 2008; Yeo & Moore, 2003). The end result for those with disability is a lack of opportunity to improve their situation and to develop as people to their full potential across various sectors. This impacts on the value placed on them by a society who judges on a comparison with “perfection” and discrimination and fewer opportunities in life are the most likely outcome for women with disabilities.

Stereotyping, stemming from within the family, portrays women with disabilities as a burden and embarrassment to them, which could be observed to be another cause and means of segregation (Mitra & Sambamoorthi, 2009; Armstrong, Armstrong &

Barton, 2000). The INWWD (2010) supported the notion of discrimination from the family, which dispels the involvement, and opinion of women with disabilities. There is poor awareness in families that women with disabilities have more to offer. The family and disabled people need to be contacted and assessed to identify the potential of the person with disability, so they could be assisted to take advantage of opportunities.

Feminism implies an obligation and interest to raise the dignity of women with disabilities (Hesse-Biber, 2012). It has been purported, however, that the group with the disability is itself responsible for counteracting discrimination through appropriate attitudes in order to overcome their situation, and in order to improve conditions. On the other hand, there is an alternative proposition that disability is a social construction. Societal constructs are the control mechanism through which persons with disabilities are marginalized, and denied expression. Therefore, the view that the responsibility is in the hands of individuals with disabilities is untenable. Society and culture itself must change (Hesse-Biber, 2012; Beckmann et al., 1989). This conflict of opinions has been debated continuously. Without public acceptance, the disabled population will not be able to voice their opinions. Yet, without the participation and opinions of the disabled community expressing their needs, people will not understand the inside world of the person with disabilities. Moreover, because disability is very diverse, persons with disabilities can be considered as distinctive groups and their collective voice is further weakened. Emphasized femininity is related to adherence to social norms about what or how a woman should be. Modern non-disabled women began to fight for the right not to conform to feminine styles (i.e., particular clothes,

food preferences and characteristic behaviours) and rejected the lifestyle discriminations that differentiate women from men. Opposed to this feminist stance, women with disabilities desire femininity; they want to be recognized sexually (Begum, 1992). They desire acknowledgement that they are women and therefore follow established female customs.

Women with disabilities tend to be left out of beauty advertisements, where established beauty concepts and standards align with the pursuit of the perfect body, most widely accepted by culture and society (Erickson, 2007; Dyck, 1996). Emphasized femininity is a paradigm that is aligned to patriarchy (Morris, 1989). It is welcomed by society and accepted in the community. For women with disabilities, this means they strive in the arena of womanhood, rather than disability. It can be presumed that in fact, women are more likely to embrace this feminine perspective because of its alignment with the patriarchal system embedded in all society. This stance is diametrically opposite to the radical emancipatory perspective that seeks to empower women in a world dominated by men.

2.5 The concept of access to healthcare services

Many studies have attempted to explore the relationship between healthcare utilisation and its outcomes. They identified that access is the mediating process between the availability of healthcare and consumer utilisation (Penchansky & Thomas, 1981). Access arises from a physical infrastructure. However, this observation was made of health environments in developed countries, without reference to developing countries. Penchansky and Thomas (1981) then elaborate on the concept of healthcare

service distribution. They argue that to establish supply equal to demand, requires availability, accessibility, accommodation, affordability, acceptability, and continuous services. However, if one factor fails to be fulfilled, the inequality of healthcare services will prevail (Penchansky & Thomas, 1981). This draws attention to the relationship between policy-makers and society who both influence the distribution and quality of decisions regarding infrastructure.

Access to healthcare services continues to be debated with no clear definition of healthcare access in the literature (Whitehead, 1991). Much of the literature broadly defines healthcare access as a complex but integrated health system providing services obtained by individuals at anytime and anywhere (Levesque, Harris, & Russell, 2013; Gulliford et al., 2002) and as such are influenced by multifaceted social determinants and characteristics, i.e., age, gender, social status, economic, environment, and technology which influence utilisation and outcomes (WHO, n.d). In order to achieve a healthy quality life, an accessible healthcare service is imperative. To be able to offer equal and equitable access, healthcare services must provide proper health treatments according to the diagnosis and personal needs of individuals and should be accessible, regardless of whether it is utilised or wanted (Whitehead, 1991; Levesque, Harris, & Russell, 2013; Gulliford et al., 2002).

Equity includes equality in its construct. When any individual is in need of a healthcare service, they should have the same opportunity to access and utilise it, despite a decision to actually use it or not (Culyer & Wagstaff, 1993). Within an equitable health system, access is expected to properly meet any individual's health

needs for any reason. This does not mean equal access is achieved. It depends on the subjective measurement of characteristics of society. Equality as a concept includes subjective variables that influence individual decisions to utilise the service, decisions which are influenced by social demographics such as financial, geographic, beliefs and other characteristics. This variety of influences makes it difficult to observe which of them influenced a decision to access the healthcare service. When subjective considerations, rather than medical factors alone, influence healthcare utilization it creates inequitable access and disparities. In contrast to equality, the equitability has the strength through the use of objective variables to measure actual healthcare utilisation, i.e. quality, time, affordability, and distribution. Therefore, the availability of access to serve the same need for different individuals will be difficult to meet.

Culyer and Wagstaff (1993) pinpointed equity as the need of healthcare (horizontal) and the proper treatment received according to the level of need (vertical). It is easier for governments to imply equitability rather than equality because governments could prioritize and decide on suitable healthcare services. Its policies need to determine the services' quality and consistency of distribution in order for it to be equitable. The challenge of delivering an equitable health system is the failure to synchronize policy with its implementation programs, causing the misdistribution of the services and a further challenge lies in providing quality services, e.g., healthcare centres, health worker knowledge, and the individual's financial ability to pay for health services (Culyer and Wagstaff, 1993). Self-dependency will influence an individual's inclination to obtain and utilise healthcare services. Yaakoubd (2009) identified the

collaboration between individual characteristics and society's attributions as a factor responsible for the location of healthcare services. This concept is formed by collaboration between money distribution, resources, and their interaction within the society (Yaakoubd, 2009). Further explanations identified socio-economic and cultural dimensions as a part of healthcare acceptability in the society (Levesque, Harris, & Russell, 2013; WHO, 2005). The relationship between the individual and the society determines whether they will accept or decline certain healthcare services delivered by their social system. Thus, society is the decision maker and the judge of whether to accommodate or to deny access to healthcare services.

A number of studies reported that individual characteristics are the lead factor of healthcare utilisation, supporting the view that an individual's background influences their willingness to obtain healthcare services even though the supply may be unavailable or challenging (Friel, 2009; Levesque, Harris, & Russell, 2013). They argued that healthcare access is influenced by financial, non-financial, and individual attributes e.g., cultural, education, employment, knowledge about health. These factors are embedded in the decision-making process, especially economics. The lower the economic capacity of individuals the lower the access to healthcare services resulting in isolation from the services which was highlighted as a contributing factor to individual health outcomes in light of accessibility and availability of the healthcare services (Friel, 2009; Yaakoubd, 2009). Another factor taken into consideration by the individual is the culture within society. Culture refers to the established values used as a guide by an individual and which society accepts as a norm, including healthcare. Boundaries

between the cultural and social dimensions are difficult to differentiate because social participation is linked to culture, which is translated into social practices (Yaakoubd, 2009). Cultural attribution through ethnicity, acculturation, and other interconnectedness has a major impact because of its beliefs about diseases and its traditional practices that can be deemed to substitute modern health services (Friel, 2009; Levesque, Harris, & Russell, 2013; Yaakoubd, 2009). For certain ethnic groups, the cultural dimension has an important relationship to health concepts. It is a topic that requires further study due to the cultural diversity involved. Specifically, in the health field, the cultural aspect of socio-cultural determinants should be included in the study, in order to understand the concept and the requirement to substitute it with traditional healthcare.

The literature also suggests that the physical dimension, e.g., time and space, is a part of healthcare availability. From a user perspective, the time required to receive the service and to travel the distance from home to the service location is a concern (Eberhart & Pamuk, 2004; Levesque, Harris, & Russell, 2013; Penchansky & Thomas, 1981). This factor is related to the extra cost and time required for accessing a service, rather than the availability of the service itself. When there are boundaries to this, it is linked to longer times and higher costs in accessing healthcare services. However, healthcare service access is also affected by the unavailability or shortage of healthcare personnel and providers or their geographic distribution within a community, including their infrastructure resources to deliver the services.

Disproportional distribution of healthcare personnel and healthcare providers occurs in rural areas (WHO, 2005). Rural areas present more challenges for patients compared to urban areas when accessing healthcare services (WHO, 2005; Eberhart & Pamuk, 2004). The patient experienced longer waiting times for treatment or a shorter service time delivered by the provider. This could mean users do not receive the fullness of appropriate treatment required and providers may not accommodate sufficient information and treatment for their consumers. Overall, the literature suggests that to produce equitable healthcare in order to yield a good health outcome, the healthcare concept needs to incorporate integration with factors outside of health dimensions, such as individual and social factors.

2.5.1 Healthcare need among women with disabilities

Women's decisions to access healthcare services are influenced by many factors, including personal characteristics, available time to access the resources, financial benefit when accessing the services, and her personal priorities (Bird & Rieker, 2008). Women, for example, have a higher health literacy compared to men (Kolb, 1981), increasing their likelihood of seeking help. However, health and social research require collaboration in exploring gender differences. Further research is required to understand the relationship between women, disability, and health. OHSU (2008) pointed out that women with disabilities are less concerned about female-related health problems compared to the remainder of the population. They are more worried about being a burden or about their previous bad experiences (OHSU, 2008).

Women with disabilities tend to more frequently access healthcare services

compared to able-bodied women. This care could be in relation to their disability specifically or for their general health. With the medical model, disability is treated as an illness; therefore requiring curative or rehabilitative treatment. However, with the emergence of the social model, it argues that disability is different from the illness *per se*. According to Imrie (2004), disability and illness are distinct and required to be treated differently. Disability could be as a result of a chronic illness that needs to be treated as a disease and requires medical attention. However, it is not necessary that someone with a disability is sick. Disability requires other interventions to assist the person in daily living, and this might be non-medical treatment.

Women with disabilities need the healthcare services to address their individual needs, to manage their health, and to prevent the possible adverse health consequences from their disabilities. They require access to prevent, promote, and maintain their physical and mental health from deteriorating to chronic conditions where possible (Wisdom et al., 2010). It has been pointed out that women with disabilities pay less attention to specific health problems, resulting in less likelihood that they will access healthcare services (Wisdom et al., 2010). Also, it is known that disparities to access healthcare need are common in women with disabilities (OHSU, 2008; Wisdom et al., 2010; Thomas, 2001). Studies have shown that women with disabilities are most likely to be disinclined, and hesitant, in meeting their own health needs (Poplewell et al., 2014; Bradbury-Jones et al., 2015; Barry et al., 2009). External factors that contribute to this reluctance to access health services include the poor attitude of midwives, doctors, and health workers in general who, it is claimed in this

study, did not ask permission when performing pelvic examinations (Bradbury-Jones et al., 2015). Such attitudes toward women with disabilities can also be scrutinised in context of other obstacles such as the poor perception of women with disabilities; the women with disabilities' low self-esteem and society's poor perception toward them; and limited knowledge of women with disabilities regarding treatment received in maternity services (Beckmann et al., 1989; Bradbury-Jones et al., 2015).

Such attitudes deter women with disabilities from questioning or complaining about the quality of care they received. Devaney et al. (2009) identified a number of constraints for persons with a physical disability when accessing cancer scans, including systemic, architectural, procedural, and attitudinal. However, the constraints to accessing healthcare are not limited to physical restrictions and attitudinal factors. This study points out the gaps in policy, the lack of information on how the disability affects health, and limited financial and personal assistance are all deterrents for women with disability (Thierry, 2004). Along similar lines, Turk (2004) added a discussion on the lack of healthcare providers' certification requirements related to the treatment of individuals with disabilities, the absence of which results in a lack of knowledge and skills linked with unhelpful attitudes.

There is also a disincentive for health services in treating women with disabilities. Their care is more time-consuming, resulting in poorer financial incentives when fees for care are compared to the care of non-disabled women. At times health services are under-resourced and at times do not have appropriate procedures in place to meet demand for services. Reis (2004) commented on the unavailability of

translators for persons with hearing disabilities. Clinicians do not ask family members to provide a translator when examining patients. Frequently clinicians examine a patient in a wheelchair instead of on the examination table or use the security guard for assistance rather than a health worker to move patients from a wheelchair onto the examination table. Dennis (2004) reported the discovery of a policy in the USA that allows doctors to refuse to examine patients with disability or to refuse a patient if she/he cannot climb up to the examination table independently.

Access to healthcare can be fraught with difficulty. The building design, infrastructure, and non-accommodating examination equipment in health centres present a number of physical barriers to accessing care (Vehmas & Makela, 2008; Wei, Findley, & Sambamoorthi, 2006; NYLPI, 2012). Alongside such physical obstacles, other contributing factors were identified, such as biases, lack of training/knowledge of health professionals, and the community's prejudice and stigma toward disabled women (Human Rights Watch, 2010; Morrison et al., 2014; Lipson & Rogers, 2000; Bradbury-Jones et al., 2015). These concerns have been raised in the discussion above, regarding the social model of disability.

Difficult to access infrastructure; the design of healthcare services and its equipment has resulted in this group of women rarely having medical examinations, e.g., pap smears or mammograms (NYLPI, 2012; Beckmann et al., 1989; OHSU, 2008). This situation is a common event in the countries with unaccommodating healthcare services for women with disabilities, including Indonesia. Therefore, a higher number of disabled women are unable to access cancer screening services. Rather than effectively

addressing this inequity, health centres are reported to have chosen to cancel an examination rather than facilitate access for the patients. Their reasoning is that the patients are considered not sexually active and are deemed a low risk for cervical cancer (Wei, Findley, & Sambamoorthi, 2006).

A qualitative study by Morrison et al. (2014) explored access to maternal services in Nepal. The participants were 27 women with disabilities, who had received maternity care within the previous 10 years, and five midwives. The findings showed that miscommunication proved to be a gap between health professionals and disabled female patients. This had important implications e.g., when making decisions on whether to deliver at home or at the hospital. The study suggested that health providers ought to introduce some form of assistance to bridge communication barriers.

Another qualitative study by Bradbury-Jones et al. (2015) investigated the experiences of five women with disability in Scotland, to understand their experiences accessing maternity services for care related to domestic violence incidences that happened during their pregnancy. The number of participants was limited making it an underrepresented population and which impacted on the transferability of the results. Also, the sensitive nature of the issue made it difficult to attract participants. These authors concluded that violence shapes negative attitudes of women with disabilities' toward maternity healthcare because of worry about double judgement for being disabled and for being subject to domestic abuse. It also found that the health workers provided an empowered treatment and information to assist women with disabilities to make maternity decisions for themselves.

Women's health needs include services for general health, women's health, and disability health. The literature suggests that the healthcare needed by women with disabilities to be able to live a healthy life is equal to that of able-bodied women. Whether for preventive medicine, promoting good health, or maintaining health, disparities between two groups still occur. Given the fact that women with disabilities have unique needs, the evidence still shows that healthcare providers fail to provide the proper services and women with disabilities fail to have their healthcare needs to be met due to challenges in access. Additionally, women with disabilities and able-bodied women could be affected similarly but respond differently to the same health issues.

Healthcare workers see women with disabilities as a group that does not require sexual and reproductive care (Phillips & Phillips, 2006; Nguyen, Liamputtong, & Monfries, 2016). Sexual health in practice for women with disabilities is still a neglected research area, with current studies tending to focus on sexual rights and sexuality (Servais, 2006). Common misconceptions regarding the sexuality of disabled women are noted as: "In society, women with a disability are considered asexual and not eligible to be married or be mothers" (Altuntug et al., 2014, p. 222). Unattractive, undesirable, unable to determine their own sexuality is how women with disabilities are seen, because they are considered to be ill, and their illness influences their sexual desire (Basson, 1998; Nguyen, Liamputtong, & Monfries, 2016). Even though women with disabilities have the same concern regarding general health and women's health as able-bodied women, having disabilities and its sequelae illness, could affect their sexual needs and repress them.

Attention to sexual care issues was raised by Beckmann et al. (1989) in a quantitative study conducted with 55 women aged 20-69 years old in the USA that identified the need for sexual information and counselling. The participants had an acquired or congenital physical disability without a cognitive disability. The sample of participants was recruited from a disability conference, a rehabilitation centre and through a magazine advertisement. The study reported that approximately 45.3% of women wanted information and/or counselling about sexuality. Even so, only 5.5% actually asked about sexuality in communication with their healthcare providers. Others chose passively to be asked by the health service regarding these sensitive issues. Those who were prepared to initiate this discussion with their healthcare provider indicated that the participants were accepting of their sexuality and expected that the healthcare workers would be comfortable to provide information and discuss sexuality with them. Health professionals' opinions of women with disabilities are also scrutinised. Several studies reveal that health professionals raised questions about the capacity of women with physical disabilities to participate in sexual activity, and queried their reproductive capacity and their ability to care for their children, even suggesting that this group would deliver disabled children (Human Rights Watch, 2010; Morrison et al., 2014; Lipson & Rogers, 2000). Misinformation creates unsatisfactory treatments, as studied in Uganda, Nepal, and Tanzania. The relationship between poor quality of treatment and prevailing attitudes is consistent (Greenwood & Wilkinson, 2013; Human Rights Watch, 2010; Morrison et al., 2014; Andersson, 2010). This influence on the quality of healthcare for women with disabilities as revealed in international studies further

magnifies the necessity for the current study to investigate the problems Indonesian women face in terms of health policy, healthcare access and how the government addresses these matters.

2.6 Disability management, policies, programmes, and projects

2.6.1 Disability management, policies, programmes, and projects by other countries

It is imperative for disability stakeholders to contribute to disability management for a good number of reasons. The World Report on Disability 2011, demonstrated that policies and programs for disability are endeavouring to engage and recruit persons with disabilities as stakeholders (individuals and organisations), rather than relying solely on opinions of experts and scholars from the field of disability (Tomlinson et al., 2009; WHO, 2011). Tomlinson et al. (2009) considered that experts' views supported the need to improve health policies, systems, and services for persons with disabilities by focusing on optimum interventions for disabilities. Amin et al. (2011) promote the involvement of advocacy agencies and submissions from the persons with disabilities to influence the development of better systems, strategies, and programmes, and to add to the body of knowledge, and in this way to generate robust evidence and reliable databases. Research challenges health policy revisions and policy writers to include a person with disabilities in this process, concentrating their efforts on identifying barriers to healthcare access and participation and establishing standardised measurements of disabilities, intending to

incorporate comprehensive information into the development of improved health systems.

Looking at the policies and programmes of developing countries, governmental authorities admit that current programmes still only cover basic needs rather than having a well-established overarching policy (Mprah, Anafi, & Sekyere, 2014). Such policies ought to be in place to guide the development of robust disability programmes. Programmes that improve the person with disabilities' basic activities of daily living and which facilitate inclusion in normal society are frequent. For example, programmes in Malaysia and the Philippines grant certain financial living allowances and provide assistance for public housing/home rental, along with exemption/discounts in health costs, appropriate accessible amenities, and tax breaks for people/family members and for companies that employ people with disabilities. South Korea and Japan even include entertainment and recreational programs in welfare benefits, in their endeavour to create better equity, and furthermore, offer other benefits such as free or discounted airline tickets, cinema tickets, internet fees, public transportation fares, and even subsidization for educational/training through the Academic Bill of Persons with Disabilities in 2015.

The current international thrust is directed towards rehabilitation through a "social disability" approach which focuses on elimination of barriers, e.g., in access to building infrastructures; and on better designs of buildings (Evcil, 2009; Reynolds, 2010; Tongsiri & Riewpaiboon, 2013; Welner & Hammond, 2009; Hanson, Neuman, & Voris, 2003; Iezzoni & O'Day, 2006; Goodman et al., 2007; INWWD, 2010).

One study in Ghana by Mprah, Anafi, & Sekyere (2014) showed that there are consistent factors that contribute to on-going discrimination against disabled women. These influences include cultural and economic elements, as well as beliefs in supernatural phenomena. The lack of research and reliable data about disability stimulates little attention toward this group and when it does, it is either cursory or negative. Mprah, Anafi, & Sekyere (2014) review of seven major international documents, addressing the policies relevant to disability, has shown that the policy-making process is still influenced by both religious beliefs and cultural norms. Disability communities do lobby for changes in policies, yet it remains unclear why so little progress is made toward this objective. This observation is supported by Mitra, Posarac, & Vick (2011) who noted a scarcity of literature about access to healthcare for persons with disabilities in developing countries. Furthermore, Mmatli (2009) emphasized the importance of including persons with disabilities as researchers to fill the gaps in available data, and to include them also in the utilization of that data to influence the development of policy. Also as Groce (1997) suggested, cooperation and collaboration between researchers in female-focused studies and disability researchers are required in order to address the highly complex issues for women with disabilities and this should be overseen by women, to achieve authentic representation of the target group. This analysis found there is a lack of research utilization and its implementation. The reason arose from a lack of coordination between the research purpose or intention and its findings. Utilising the disabled population as the central focus for evidence-based policy development (Mitra, Posarac, & Vick, 2011; Mprah,

Anafi, & Sekyere, 2014) is a means of translating and transforming evidence regarding women with disabilities into governmental policy and into action internationally.

Over the past twenty years despite many countries producing legislation that protects the rights of women with disabilities progress is slow. Groce's (1997) recommendation was to incorporate women with disabilities into women's activities and into activity programs for the disabled; and to empower them to speak, represent, and decide for themselves regarding the improvement programmes they seek. This recommendation is consistent with a case study in Hamilton, New Zealand. Its city council included persons with disabilities for consultation and listened to what they required for an accessible city and for a disabled strategy (Disabled Person's Assembly, 2007). This method validates the claim that disability stakeholders' involvement can reduce the gaps in addressing the needs of people with disabilities.

In summary, it is important to acknowledge the contribution from the stakeholders to create programs that can accommodate persons with disabilities (Tomlinson et al., 2009; WHO, 2011; Amin et al., 2011). Consequently, it is important for the government to be aware of the potential contributions of those directly affected by disability, to create better systems, strategies, and programmes.

2.6.2 Disability management, policies, programs, and projects by the Indonesian government

Public awareness of the difficulties women with disabilities face in accessing healthcare is growing. They are therefore gaining more attention from the government. This is especially true in developed countries, which have enough resources to serve

the public by offering various comprehensive packages particularly targeted toward minority groups (Disabled World, n.d). However, in Indonesia, the issue of women with disabilities remains un-investigated by the government. A report by Tanukusuma et al. (2014) stated that women with disabilities in Indonesia continue to be a group who are discriminated against, and endure on-going vulnerability to sexual violence; sterilization against their will; discrimination regarding marital status; and inhumane treatment by society. For example, the Marriage Act of 1974 enacted by the Indonesian government, allowing husbands of disabled women to practice polygamy, demonstrates this discrimination. Additionally, discrimination is apparent in regulation Undang-Undang No. 61 (2014), on Reproductive Health, that restricts the right to abortion only if the foetus is diagnosed with a genetic defect that would be incurable when they were born or if the woman would be exposed to an unacceptable risk during pregnancy and childbirth. Society decides for the women with disabilities whether to carry on the pregnancy or abort it; a challenge in sexual and reproduction health matters for a person with disabilities.

The Advocacy Centre for Women with Disability and Children (Sentra Advokasi Perempuan, Difabel dan Anak [SAPDA]) reported on a 2006 study, which showed a wide range of relationship issues between a person with a newly diagnosed disability and their families. Interviews with sixty women found that six out of seven women are now single because of their partners' abandonment of them due to their disabilities. Even among the group who remained married after the onset of their disability, they returned to their own families, and/or experienced sexual problems because the

husband either did not ask for intercourse, was disgusted, or was uncomfortable about intimacy after the onset of the disability. Other problems experienced by the women in this study included intimate other/partner violence, sexual, psychological, and economic abuse, as well as the exploitation of government-funded assistance by the husband (Difabel News, 2010).

Since the reform era in 1998, the Indonesian government has begun to adopt a human rights perspective. Even so, the existing legislation was built on a historic perspective via the medical model, namely Law No. 4 of 1997 on Persons with Disabilities, and its implementation through Government Regulation No. 43 Year 1998 on Measures to Improve the Welfare of Persons with Disabilities. This regulation based on the medical model is considered to have nominal impact in terms of mainstreaming, and in engendering respect for human rights of persons with disabilities, and is seen as no longer appropriate to meet the complexity of the needs, nor for the protection of the rights, of persons with disabilities (UPIAS, 1976).

The Indonesian Ministry of Social Welfare has established various social institutions for persons with disabilities throughout Indonesia. For instance, the establishment of associations for women with disabilities in 1997 and the establishment of the Social Welfare Institute in Bandung, which provides a study course in disability and trains professional social workers.

In 2011, the Indonesian Government enacted Law No. 19 of 2011 on the Ratification of the Convention of Rights of Persons with Disabilities. This legislation reflects Indonesia's commitment to adopt a social perspective of disability, based on

human rights, which will contribute to efforts to address the concerns of women with disabilities. This legislation has been followed up with a few regulations to enforce it. Among these are the chief of Indonesian National Board for Disaster Management (Badan Nasional Penanggulangan Bencana-BNPB) Regulation No. 14 of 2014 on Management, Protection and Participation of Persons with Disabilities in Disaster Relief; Permensos No. 25 of 2012 on Standards of Social Rehabilitation of Persons with Disabilities by the Institute in the Field of Social Welfare; and through standardising the rehabilitation programs implemented by the social welfare organisation. In the meantime, Regulation No. 43 of 2014 of the Implementing Regulations of Law No. 6 of 2014 addressing needs at the village level, empowers rural communities in planning and budgeting in favour of the individual, in the interests of the citizens with disability (article 127 paragraph 2). Meanwhile, the Ministry of Transportation has long been implementing rules for special air transport of passengers for the Islamic hajj pilgrimage. This regulation covers disability, with updates via Permenhub No. 1 of 2013 on Service Standards Passenger Air Transport Hajj.

Local government is aligned to this initiative focusing on the needs of persons with disabilities when creating policy and in putting policy into practice. The South Sumatra Province has issued Regulation No. 6 of 2014 on the Protection and Welfare Services for Persons with Disabilities. The Ministry of Women's Empowerment and Children issued regulations that are specific to women with disabilities through government regulation No. 7 of 2012 on Standard Operating Procedures for Information. Consequently, a Consultation Centre for Women with Disabilities has been

set up. On the horizon is another positive development. It is expected that the Disabilities Act will be discussed and passed by Parliament within the next three years, before 2019. It will be under the jurisdiction of the Coordinating Ministry for Human Development and Culture. One of the functions of this body is the coordination and synchronization of policy formulation in the field of empowerment of disabled and elderly people (Presidential Decree No. 9 of 2015 on Human Development and the Ministry of Cultural Affairs).

On the basis of the evidence available, it could be argued that a positive response, although not significant, has been produced by various agencies on improving the social and physical environment for people with disabilities. With a charity-based orientation, the Indonesian government believes that financial aid will solve the problems of persons with disabilities. It views that persons with disabilities are objects that require assistance, rather than view it as a fulfilment of basic human rights. The Law No.4 Year 1997, Disability Act (Undang-Undang, 1997), as the foundation for disabilities policies showed the lack of understanding of disability from the policy-maker by combining the charity, medical, and social models into its articles. The Indonesian government needs to upgrade their knowledge of disability to understand the urgency to reform the policy for disability and to be able to create a non-biased and non-discriminative policy. Due to its multi-dimensions, disability requires integrated inter-agency policies led by the government. Currently, the focus is still on the social-welfare dimension with appointed responsibility in the Ministry of Social Welfare; with additional policies from other agencies dependent on which sector

is most relevant. Even though the Indonesian government signed the Convention on the Rights of Persons with Disabilities, its regulations still fail to embrace human rights as stated in the ratification. The Indonesian government should have a deep knowledge of disabilities and its policies should be comparable with other countries who have been able to create their policies with the Convention on the Rights of Persons with Disabilities guidance in meeting human rights for disability in their respective countries. Emerging from this discussion is how women with disabilities have viewed the existing management, which affects their access to healthcare services, the enquiry of the present study.

2.7 Indonesian government policies and programs for disabilities

Indonesian government policy affecting people with disability has seen change and progress since 1945. Based on the original Constitution of the Republic of Indonesia in 1945, article 25 stated that an Indonesian citizen is anyone who is a native Indonesian, with the assumption this includes people with disability. This constitution had been amended during the period 1999 - 2012. Article 25 developed into article 27 and 28, detailing human rights for Indonesian citizens (Hukum Indonesia, 2014). It stated that every citizen has the right to be free from any type of discrimination and to receive opportunities or treatment to achieve equality and equity in quality of life. Even though the amendments did not clearly mention people with disability, it was a significant improvement in human rights for Indonesians. This also established a good foundation and influence early in the constitution for people with disability to recognize their equal position in society as able-bodied people. Since people with disabilities'

rights and voices are often neglected and violated, and further because they are seen as inhuman and ignored as a part of society, a change to their rights toward inclusivity in the country's development is essential (Arinanto, 2008). These amendments affect the existing concept of disability and ensure that any act, government regulation, presidential and ministerial decree toward disability that is delivered, founded within the constitution of 1945, will need to be revised and adjusted according to those adjustments to the constitution. This is especially so with the Indonesian government already having signed the ratification of Convention on the Rights of Persons with Disabilities (CRPD) in 2011, showing that the Indonesian government is committed to work and honour the rights of people with disability.

Alongside the regulations produced by the Indonesian government, definitions and demographics of disability in Indonesia are still confusing and overlapping. Governmental Ministries overseeing disability are the Ministry of Health, the Ministry of Social Affairs, the Ministry of Education, and the Ministry of Public Work. Depending on which Ministry caters to the needs of people who are disabled; there are various concepts and definitions generating conflicting data regarding the population of people with disability. Confusing definitions and demographics of disability are common in developing countries. The Mont (2007) report for the World Bank revealed that various concepts and definitions regarding the measurement of the prevalence of disability were used by different agencies in a single country. Mont (2007) considered that different statistics are reported because of differences in the definitions of disability, differing methodology in the data collection, and variations with respect to the

interaction between people with the environment. Differences in the analysis of disability show up in the prevalence rates. Indonesia is one of the countries in which data is inconsistent for this reason. Comparison of data using the Indonesian Ministry of Health and Badan Pusat Statistik (BPS- Central Agency on Statistics) data, showed the similar prevalence of disability from 2007 to 2013 where the numbers of women with a disability are higher than men. Over time the data shows the ratios of female to male with disability inconsistently. According to Badan Pusat Statistik 2014 data (BPS- Central Agency on Statistics, 2015) based on gender grouping of the population aged 15 years and above, the numbers of women with disability is consistently higher than men. In 2007, 21.5% of women and 17.4% of men were recorded to have a disability; in 2013 these numbers were just 12.8% for women and 9.2% among men (Kementerian Kesehatan, 2013). However, the consistently higher number of disabled women group was not evident in data from Central Agency Statistics data in 2010. Women's higher prevalence was a much narrower gap of just 0.3% in that data set (women and men's prevalence rates were 25.4% and 25.1% respectively) (BPS, 2010). This gap between Ministry of Health and Central Agency Statistics could be a result of different methods of the surveys used regarding people with disability. The Ministry of Health referred to the World Health Organization's Disability Assessment Schedule 2.0 (WHODAS 2.0) method, using the questionnaire for people who have disabilities to rate their difficulties in the following categories: vision, hearing, mobility or climbing stairs, concentration, cognition, and self-care. Conversely, Badan Pusat Statistik (BPS - National Statistics Agency) referred to the Washington Group instrument to grade the difficulties in people

with disabilities' daily lives as part of the impairment scale. Also, BPS has its own standardized concept of disability, a merged concept between UNFPA, WHO, and UNICEF definitions, with the intention to be able to produce comprehensive, accurate, and standardised data for different ministries or sectors (BPS, n.d). Where demographics on disabled populations are unreliable, this can impact on the implementation of policy. Based on the information related to confusing and overlapping data, differences in figures can create poorly synchronized programs that suffer from inconsistent implementation and which fail to meet the needs of target populations (Mont, 2007). Improved and more effective management, to synchronize and coordinate stakeholders (academia, disabled people's organizations, and research organizations), is needed to produce accurate demographic data of disabled populations, and well-targeted implementation of policy (Arinanto, 2008).

The evolution of Indonesian policy toward disability began in 1945. Protection for disabled people in Indonesia was evident from Indonesia's year of independence, 1945, when the constitution mentioned that every citizen has the right to be protected by the government. This includes the disabled population (UU, 1945). It was not until 1997, that a regulation (Law No. 4) was created, based on the United Nation's Declaration of The Rights of Disabled Persons, 1975, addressing the rights of access for persons with disabilities. Access here refers to education, employment, rehabilitation and social welfare, and includes the right to grow and enjoy participation in society, similarly to non-disabled individuals, and the right not to experience discrimination. This regulation is even now, not being carried out as expected. The weakness of this law was

the emphasis on rehabilitation and social welfare, which is oriented towards a medical and charitable model of intervention. Though the purpose was noble, implementation excluded persons with disabilities from social activities, e.g., by attending special schools or special rehabilitation centres, rather than including them in mainstream schools or activities, thus, a child was alienated from his or her peers. This implementation relied on the medical model of disability, which portrayed that when someone has a disability, he/she is limited in activities, and disability is seen as an illness requiring a clinical treatment or rehabilitation by healthcare services. A further concern with this law was the perception of the disabled person as an object, an impression arising from the medical model and framework. Within this perspective, because of physical and/or cognitive imperfection and the inability to undertake normal daily activities, disability was seen as an obstacle that needs to be rehabilitated in order for a person to be normal. Consistent with this narrow view of disability, the approach adopted was not through multi-sectoral collaboration, but exclusively through the Ministry of Social Affairs (Indrati, 2007; Daming, 2003).

The growing understanding of disability from a social perspective occurred when the Indonesian government began to adopt a human rights perspective for persons with disabilities in 1997 when the government produced several new regulations. Since the shifting of the perspective of disability, the Indonesian government revised the definition of disability through clearer and more comprehensive details, a coherent definition of disability, and the measurement of welfare of people with disability in comparison with the general population. Further shifts in understanding were

evidenced in the National Government Regulation No. 43 (1998) to promote the Welfare of Elderly and People with Disabilities. This regulation stated that people with disability are part of Indonesian society with equal rights, obligations, and opportunities as were available to the able-bodied group. To create equality, the Indonesian government facilitated this through efforts to boost the welfare of people with disability. Even so, according to the standards upheld by the Convention on the Right of Persons with Disabilities, the regulation No.43 (1998) is seen as an unsuccessful policy. From the participants' observation, despite the government's noble intention, the policies' purposes have not necessarily been reflected in action. Its implementation failed to integrate the person into society, lacking in providing adequate facilities, and insufficient in protecting their rights.

Another progression for people with disability in Indonesia was from Central Government. It created Law No.25 in 2009, regarding Public Services and infrastructure access, and was intended to ease access for disabled. This law satisfied human rights from the disability perspective, however, it has not been utilized as guidance in public building access regulation. Difficulties and segregation continue to be experienced. According to the policies introduced above, efforts to facilitate the shifting from the medical model into social model perspective were indeed provided by the Indonesian government. However, the government's effort to improve infrastructure, regulation and service for people with disability is still in evolution. In order to achieve a comprehensive definition of disability, a development and integration of disability concept is required, coupled with the rights and obligations of people with disability,

and legal certainty. This is necessary to establish reliable and attainable access for the disabled.

Advanced action from the Indonesian government occurred when the national government published Regulation No. 19, in 2011, for the Ratification of the Convention on The Rights of Persons with Disabilities. This regulation required the Indonesian Government to commit to improving, protecting and fulfilling the rights of persons with disabilities, and was compatible with the purpose of the Convention and simultaneously established Indonesia's intention to adopt a social model of disability. The government is now obligated to protect the basic rights of persons with disabilities. The ratification is open to interpretation in the myriad of ways it may be translated into everyday life and does not guarantee comprehensive coverage for disability in general. For example, further explanations may be required regarding the definition of discrimination against persons with disabilities, or greater guidance on how to apply the ratification to daily activities. Thus, it behoves the Indonesian Government to create and enforce additional regulations to ensure that tools and strategies are in place to organize, manage and supervise the process. To synchronise the Indonesian government's programs with the Convention on the Rights of Persons with Disabilities standards, actual measures of discrimination against persons with disabilities and the practical impact of the ratification on daily lives need clarification.

Laws and regulations from the Indonesian government focus on people with disability, with nothing specifically for women with disability. Even though the Ministry of Women's Empowerment and Child Protection was formed in 1978, it was not until

2012 that it delivered a significant policy specifically for women with disability through regulation No. 7 (2012) on Standard Operating Procedures for Information and Consultation for Women with Disabilities and Children in Social Conflict Situations. This procedure complemented the policy formulation from the Ministry of Education and Culture to empower the disabled and elderly person (Presidential Decree No. 9 year 2015 on Human Development). Within this decree, within Article 25, it is not clearly stated how coordination and synchronization of the empowerment program should be conducted, rather it needs to coordinate with other ministries or organisations related to women and children.

The Indonesian government has a history of being attentive to people with disability since the country's independence in 1945. Even though it wasn't clearly stated in the Constitution of the Republic of Indonesia, the form of support for people with disability was amended in act, law, regulation, and decree via its ministries. Regarding the development of regulations for disability, one of the criticisms was the confusion of disability demographics and the lack of integration and cohesion between governmental agencies and efforts toward implementation, leading to a slow evolution of comprehensive guidance for disability. Attention to women with disabilities still requires a lot of work. It is still uncertain whether present developments are able to make a real difference in their lives. And the government has obligations, not simply by passing legislation to improve conditions for people with disability, but also to follow through and ensure that the policies are borne out in the process in disabled communities.

2.8 Yogyakarta city as the study location

According to data from 2011, the Yogyakarta population is 3,487,325 million people, including 25,264 persons with disabilities (BPS, 2013). Yogyakarta's government is considered to be attentive to public policy, including services for the disabled population. The local government has developed regulations and programs that uphold human rights for disabled people; examples of these programmes are discussed in subsequent paragraphs.

The Yogyakarta government in its role as a local authority has developed several regulations and practical programs for people with disability. Nevertheless, further improvement is needed. Yogyakarta has sought to address the needs of the disabled population through improvements to public transport and in access to facilities. This commitment was honoured by local government through the regulation No.11 year 2002, requiring buildings to provide access for disabled people. The current implementation of this regulation with regards to public transport has not been successfully implemented due to the public transportation association not designing buses to accommodate the needs of people with disabilities (Rahayu, Dewi, & Ahdiyana, 2015). As for buildings, the government has built ramps in public buildings and also painted yellow markers on pavements to mark them as disabled-friendly thoroughfares.

Financial and fiscal intervention to assist the disabled population was also launched by the Yogyakarta government. On-going social welfare programs and interventions include assisting persons with disabilities and their families to earn an income through productive programs and assistive materials. An example of this

empowerment program for disability was in 2012, where 20 people with physical disability trained in entrepreneurship. They were taught the theory of business concepts and process and in the field, skills for marketing, production, accounting, and management of a small business such as a shop. It was expected that a successful person with a disability will create employment opportunities opening up positions for other disabled people (Solider, 2016). Regarding assistive aids, in 2012 a collaboration between the Ministry of Social Welfare and rehabilitation centre YAKKUM the provision of aids such as wheelchairs, hearing aids, canes, etc. was facilitated. Another program, founded on central government policy was inclusive education whereby public schools accept disabled students with the underlying purpose of preparing them for integration within the community. This represented a radical move from established programs where the students with disabilities went to special needs schools making them exclusive and separated from their community. The Yogyakarta government adopted regulation No.47 in 2008 to strengthen the implementation of inclusive education, superseding previous programs in order to accommodate the social model of disability (Jogjakota, n.d).

In health, there are government-funded schemes with limited treatment and pharmaceutical provisions which do not fully accommodate the needs of people with disability, e.g., for crutches, wheelchairs or artificial limbs, hearing aids, etc. (BPJS, 2014). The latest regulation for recognising and providing for the rights of people with disability (see law No.4, 2012) requires the government to provide access for disabled people to education, health, and employment (Perda, 2012). It contains the guarantee

from the government for disabled people to be able to access inclusive education, and commits to subsidising companies that hire disabled people; and to subsidising healthcare costs. This is in addition to existing regulations in health, social services, politics, natural disaster, housing, and accessibility. However, these programs still focus on the general disabled population rather than targeting the specific needs of women with disabilities and the question remains as to whether the implementation of policy is borne out in practice for them, or whether further work is needed, extending beyond current policies.

To answer this study question, how policy in healthcare services for women with disabilities in Indonesia ought to be developed, this will be discussed in the implications and recommendations for policy makers' section. Before 2002, Yogyakarta legislation and programs deferred to national legislation, but from 2002 Yogyakarta developed its own programs according to the local need. Even though existing legislation did not focus on women, Yogyakarta's efforts comprehensively catered for the most neglected sector (education and employment). The Yogyakarta local legislation for disabilities is listed in

Table 2.

Table 2. Local legislation addressing disability and woman in Yogyakarta

Legislation	Number/Year	Provisions
Regulation	11/2002	Access for disabled in public facilities.
Regulation	47/2008	Intensive implementation of inclusive education.
Regulation	4/2012	Protection and Fulfilment of the Rights of Persons with Disabilities.

Source: Data from Jogjakota, Peraturan Daerah.

2.9 Literature review summary

The medical model is not considered a satisfactory framework to disability stakeholders because this model does not accommodate the various factors that influence the lives of those living with disability; nor does the medical model in its application acknowledge that someone with deficiencies could live independently. The medical model denies that there is any aspect of “normal” in a person who has a disability. This paternalistic way of viewing disability has resulted in decisions regarding a person’s health, being made by health workers, rather than the person themselves. In contrast to the medical model, the social model arose from a social and cultural construction; a belief that impairment is different from disability and that they are not dependent on each other. The social model does not see the medical aspect of a body as a sum of functioning or non-functioning parts and ignores the impact of disease or illness (impairment), e.g., pain, fatigue, paraesthesia, degeneration, etc. as the cause of the disability requiring medical assistance (rehabilitation, treatment). It also ignores the cognitively disabled population, focusing only on physical barriers found in the environment and on societal attitudes. Seeing these as the major factors that foster disability, it fails to emphasise the physical and bodily elements of the persons with disabilities in its perspective.

With few available studies and limited literature on this subject, it is difficult to formulate and implement an effective policy that ensures equal access to health services for disabled women in Indonesia. Given the conditions described above, the proposed study aims to tap into the experiences and stories of this vulnerable sector of women to identify the issues from their perspective, when seeking health services. By

integrating findings from the existing literature with the analysis from participants' interviews, this research can be used by the government as part of the current review it is undertaking for its disability legislation/act. These findings about global and Indonesian healthcare policies offer preliminary groundwork for carrying out the primary investigation into the health policy in Indonesia as perceived by women with disabilities. The examination of the two different models – the medical and social frameworks regarding persons with disabilities – has offered an in-depth rendering of different views on women with disabilities within culture and society; as well as within the medical and healthcare services and their practices when providing support to disabled women. This exploration of policy has culminated in the examination of the effectiveness of current policies in Indonesia.

Governmental efforts to assist people with disabilities are not always effective in bringing about the desired outcomes. In fact, quite the opposite occurs when special treatment creates additional discrimination against women with disabilities. Furthermore, current studies on disability focus on overcoming oppression and on accommodating human rights, while paradoxically, the complex issues of women with disabilities as a distinguishable group suffer a lack of exposure and attention.

Research has indicated that women have a higher risk than men of disability and of experiencing subsequent poor health, and evidence has shown that feminism and gender differences are factors that shape the women's perspectives and influence how they manage their disabilities. Consequently, the review of the international literature highlights various factors that need to be taken into account in the process of

establishing better health policies; policies with the voice of women with disabilities as the primary point of view. Partnerships between policy makers and genuine stakeholders should be established to effectively examine the problems experienced by women with disabilities when accessing healthcare, and to inspect the diverse factors that can contribute to the creation of more supportive relationships between healthcare providers and the women with disabilities and between women with disabilities and policy-makers.

The next chapter will discuss the methodology and methods used in the study, the objective of which is to gain an understanding of the perspectives of women with disabilities regarding healthcare services in Indonesia.

Chapter Three

Methodology and Methods

3.1 Methodology

This study employs a qualitative research approach, which is appropriate for understanding participants' relationships with specific phenomena, particularly where little is known about the situation being investigated (Yin, 2010). Comparing different research methods, Yin (2010), stated:

Qualitative research differs because of its ability to represent the views and perspectives of the participants in a study. Capturing their perspectives may be a major purpose of a qualitative study. Thus, the events and ideas emerging from qualitative research can represent the meanings given to real-life events by the people who live them (p. 8).

The literature review demonstrated both the complexity of the subject and the limited amount of current research. Ultimately, the goal of the study is to produce recommendations for the development of appropriate policies to improve disabled women's use of healthcare services.

Qualitative methods were first introduced by Giambattista Vico (1668-1744), an Italian philosopher, in response to the development of physics and natural sciences. Vico argued that the social sciences could not use a quantitative methodology because the social sciences are relatively systematic and complex (Fabiani, 2009). This led to the development of the constructivist epistemology (Balbi, 2008), which holds that knowledge is truth as constructed from experience. While the use of data and numbers was considered inappropriate for certain analytical processes, adherents of qualitative methodology reasoned that the use of rhetorical or narrative analysis – the use of

thoughts, ideas, or examination of everyday social life – provides a “holistic overview” for analysis (Miles & Huberman, 1994, p.6).

As each woman’s life is different, the experiences and perspectives they draw from in their responses are important in this study. Understanding their stories can provide insight into the relationship between a woman living with disability and her position in society; such understanding builds on the current knowledge of women with disabilities (Balbi, 2008). Feminist research is an interdisciplinary investigation based on the relationship between gender and social constructions. Investigations based on gender sensitivity may allow women to voice their diversity and influence the shape of gender perspectives (Hammarström, 1999, p.27). Focusing on women as a diverse group of individuals reveals multiple experiences and perspectives influenced by many factors. By relating their experiences and concerns in their own words, women’s stories can identify key issues and suggest solutions that create action; thus providing a catalyst for change and resulting in greater empowerment for women (Barata, Hunjan, & Leggatt, 2005). This study adopts feminist research approaches, capturing the truth through women’s perspectives and voices (Hesse-Biber, 2012). To make their voices heard, the feminist approach adopted in this study not only focuses on experiences of disability, but also on factors associated with disability, including gender, patriarchal culture, and privilege as societal influences (Mertens, 2007). Each woman’s uniqueness makes it important for the study to be attentive to the various perspectives of each individual.

The interplay of women and disabilities contributes to this group being

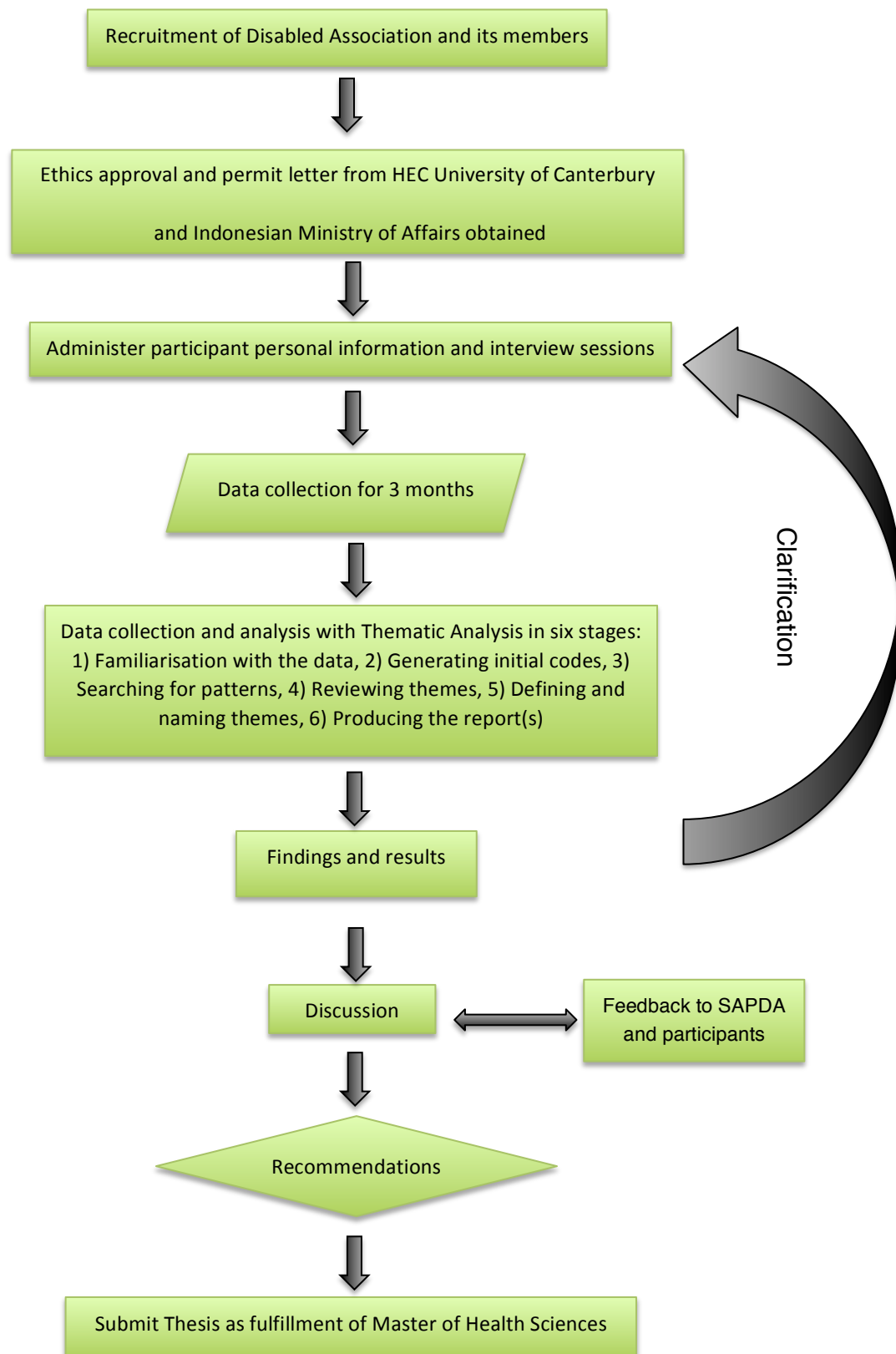
ostracised, undervalued, and under-represented (Mertens, 2007). Accordingly, a feminist constructivist approach was used to understand the relationship between gender, social, economic, cultural and political interactions. This perspective acknowledges that social injustice and inequality are experienced by women's groups as they are affected by social constructs. The existing social construct implies that women must fulfill specific roles, as wives and mothers in society's established systems. However, gender identities are evolving, so society's expectations of women may no longer be applicable. Women need to be studied independently from men because women's perspectives will enable researchers to construct women's social identities through the sharing of experiences involving both gender and disability (Hesse-Biber & Leavy, 2007). The feminist constructivist approach is grounded in the belief that culture, politics, history, beliefs and values shape the way women perceive themselves in society (Miles & Gilbert, 2005). Thus, the questions of Denzin & Lincoln (2011, p. 129) of "Whose knowledge? Where and how is it obtained; by whom; from whom; and for what purposes?" is crucial. The variety of disabilities and the factors associated with disability need to be consciously analysed. Knowing the social position, social construction dimensions, and a woman's interaction with her disabilities and the world, researchers may use that knowledge to transform society's perspectives and deconstruct existing social constructs. This also provides an opportunity to raise awareness that women experience the world differently to men, but the primary outcome of this approach should be to embrace the differences and to empower women (Hesse-Biber & Leavy, 2007).

Society is shaped by many agreed-upon influences – political, economic and religious – through observation, identification and translation using an agreed-upon language (Gergen, 1999). Knowledge as “truth” is gained only from inside society, and knowledge is then delivered to society and applied to its members’ lives through social interaction. Individual values and self-perception are affected by one’s relationship with society rather than one’s own personal experience. Decisions about the knowledge to be delivered are determined by the most dominant sector in society. The whole process shapes individual characteristics on the basis of understanding self-experiences as knowledge. Because each individual is unique in how they experience the world, knowledge keeps changing and involves a construction/deconstruction process (Gergen, 1999). In relation to women with a disability, the definition of disability is determined by the majority in societies, who are able-bodied and assume that they can represent the disabled community (Oliver, 1990). Able-bodied societal views and backgrounds influence the decision to translate non-abled bodied people’s experiences. The problem lies in the different understanding, experience, and terminology used in the discussion of disabilities and the under-represented reflections of the non-dominant group. Society’s understanding of disability keeps evolving, affecting the shape of society as awareness of disability unfolds. An example of this evolution is in the redefining of disability from a medical model, where it is seen as a biological problem, to a social model, seeing disability through an ‘empowerment’ lens.

3.2 Methods

This section explains the complete design of the study, showing each step of the process. It describes how the data was gathered and organised to achieve the objectives of the study (**Figure 1**).

Figure 1. Outline the study design flow chart.



3.2.1 Sample strategy, size, and selection

The sampling strategy in this study followed the criteria of Miles and Huberman as explained by Curtis et al. (2000). The criteria stated that to achieve the purpose of the study, the sample should produce relevant and rich information for the research question. This study employed purposive, criterion sampling. This means that the selected individuals should share certain attributes that make them suitable subjects for the study (Given, 2008). Those individuals are invited to participate in the study to achieve the research objectives, and to maintain the credibility of information (Given, 2008; Creswell, 2007). This method of sampling was chosen because the purpose of the study was to understand the experiences of women with disabilities and to obtain rich information to identify the problems and improve the health system as it relates to them. The sample also needed to be representative of the target population to provide reliable information, which is descriptive and transferable to other settings.

The sample selected were female members of SAPDA who experience disability: a group who were considered to be suitable to provide the information that was sought. This sampling type supported this study's purpose through in-depth investigation within this specific field and was expected to yield rich data. This study aimed for approximately 15 to 20 participants, with the expectation that data saturation should be achievable with this number of participants (Given, 2008; Maglivi & Thomas, 2009). Data saturation is the point where additional data collected by a researcher shows no new information in support of the study's purpose and in relation to the phenomenon studied (Given, 2008; Mason, 2010). However, this study was only

able to recruit nine participants. Therefore, saturation was not reached. This will be further addressed in the discussion chapter (limitations of the study).

3.2.2 Interview administration and strategy

A semi-structured interview was chosen as the preferred strategy because such interviews are designed to bring out the participant's detailed experiences and perspectives on the research topic in their own words, with the flexibility to explore new directions within the research topic (Chadwick et al., 2008). Individual face-to-face interviews provide a relaxed atmosphere and allow observation of cues relating to participants' attitudes. Interviews via telephone allow access to rural participants but offer no additional information such as the attitude or body language of participants (Kvale, 2007; Wengraf, 2001). Open-ended questions provide opportunities to explore and retrieve meaningful and rich explanations according to the individuality of participants because those meanings and explanations differ for each person (Luborsky & Rubinstein, 1995). This type of questioning can also be exploited as a guide for drilling down into important subjects according to the participants' point of view, rather than the researcher's (Barbour, 2008).

3.2.3 Participation criteria

Prospective participants were not limited with respect to the duration of disability, ethnicity, or religion, but they were required to be female, aged 18 years and above, and experiencing disability as defined in regulation No.19 Year 2011 (UU RI, 2011). Participants were required to be fluent speakers of Bahasa Indonesian for data

collection. In circumstances when a participant was cognitively unable to participate, a trusted family member or caregiver was permitted to give consent on that person's behalf and to be interviewed on that person's behalf. Demographic characteristics of participants, including ethnicity and educational level, were assessed according to the Population Census – Sensus Penduduk (Badan Pusat Statistik, 2010) and National Education Regulations – Undang-Undang Sistem Pendidikan Nasional (Kementerian Pendidikan dan Kebudayaan, 2003).

3.2.4 Recruitment process

Before ethics approval was issued, I contacted and followed up a number of associations for their approval and agreement to partner with them to conduct the research. The associations approached were located in Jakarta, Bandung and the Yogyakarta area. One organisation agreed to facilitate participant recruitment for this study, another agreed to participate but provided no response to my follow-up enquiries, and the remaining six failed to respond. A cooperative agreement was established with Sentra Advokasi Perempuan, Difabel dan Anak (SAPDA) who agreed to assist with the study. SAPDA is a non-profit organisation whose key concern is the health rights of women and children with disabilities in Yogyakarta. Rapport with the organisation was built to seek not only their permission but also their help to identify and recruit potential participants from amongst their membership. I explained the aims and proposed methodology of the study. Access to and protection of data was detailed, and agreement was reached between the researcher and the organization regarding access to the data. The agreement stated that any individual from SAPDA who was

involved with this research would not reveal any information about the research to a non-related party. SAPDA agreed to screen, identify and recruit potential participants for this research. The organization is a trusted party and had already established rapport and trust with the women prior to the commencement of this study.

Ethics approval from the University of Canterbury Human Ethics Committee **(Appendix A)**, and permission from the Indonesian Ministry of Internal Affairs to conduct the research was applied for and granted **(Appendix B)**. The research proposal, ethics approval letter, information sheet **(Appendix C)** and consent form **(Appendix D)**, in both English and Bahasa Indonesian, was emailed to SAPDA, who organised the information and consent forms, selected suitable participants, and scheduled the interviews. SAPDA, as the gatekeeper, contacted its members with an explanation about the proposed research in order to gain consent from their members to allow me to access their information and make contact with individuals to set up an interview time and/or to answer further questions about the research. I was then provided with the names and contact details of the potential participants by SAPDA, and I sent the information sheet and consent form to the potential participants for signing.

Additional information such as time frames and reimbursement for participants was included in the information sheet for the study. All recruitment took place exclusively through SAPDA. The bundle of documents mailed out included a postage paid, addressed, reply envelope for return of the signed agreement. For those outside of Yogyakarta, the consent form was signed on the interview day, when I visited the participant. Within Yogyakarta, participants produced the consent form on the day of

the interview, if they had not already sent it back to me. Before the interview, I contacted each participant by telephone or text, to remind her to sign the consent form for the interview. Consent was always recorded before the interview. For participants with disabilities who were unable to provide written consent (e.g., blind participants, amputees), verbal consent was confirmed and recorded prior to the interview. In such cases, a witness from the association or the participant's family/caregiver was required to be present.

Before the interview, the purpose and objectives of the research were outlined to participants. The research process was explained to ensure each participant understood the importance of completing the informed consent form and to confirm that they understood the information sheet, and their right to withdraw from the study at any time. They were also informed about the interview process, the method being used, the location and the research topic and aims. There was a reimbursement of IDR 100.000 (approximately NZ\$10 per interview per participant) as a koha to show appreciation for the time involved in completing the interview. The koha was a relatively small amount so as not to be perceived as coercion to participate in the research.

Being dependent on SAPDA's contact person to arrange members' availability and the interview schedule, I was very limited with regard to participant sample size, data collection, and data saturation. Other difficulties that arose with respect to the interviews were due to SAPDA's location. Its members mainly reside in rural and remote areas, which made them difficult to reach in person or via phone interviews

(due to limited cell phone coverage). In addition, funding constraints limited my mobility and thus my ability to travel to remote locations for interviews. The interviews were planned to run from the beginning of September 2015 to the end of November 2015, in parallel with the transcription, analysis, and writing process.

3.2.5 Data collection

Consistent with the primary purpose of this method of research, the in-depth semi-structured interviews were undertaken in Yogyakarta, Indonesia; face-to-face and via phone. I conducted one-on-one interviews using open-ended questions with women with disabilities living in the Yogyakarta area, and via telephone for participants living in rural or remote areas. It was expected that each interview would be approximately one hour in duration. Participants were provided with options, such as face-to-face interviews and locations of their choice. The location options were: 1) their own home, 2) SAPDA head office, 3) church/mosque/community centre or 4) another location of their choice. The optimal setting was considered to be the participant's own home to help maintain comfort in a convenient and private setting, which would accommodate limited mobility. A natural setting (home) also allows participants to talk comfortably in a familiar language, allowing the researcher to gain potentially important insights (Yin, 2010).

In this study, when the interview was to be conducted at a participant's home, a SAPDA representative would always accompany me to witness verbal consent and to assist with potential risks that could arise, such as evidence of depression or emotional reactions, which may be evoked when recalling distressing experiences. If the

representative identified serious risk, she was to contact a third party for assistance, i.e. psychologist, counsellor, or hospital. When a participant was a woman with a cognitive disability who was unable to give informed consent, she could appoint someone on her behalf to provide it. This could be her caregiver, a family member or someone else she trusts. Advice from SAPDA was always taken into account as the organization acted as the gatekeeper for participants. With my limited ability in special communication needs, other forms of communication were used (verbal, sign language, pictures, symbols or written cues) to support communication during the signing of informed consent forms and during the interview.

On the day of the interview, I introduced myself and continued to build rapport by providing an explanation of the study and a brief summary of the information sheet to remind participants that there was no obligation to participate in the study. I explained the process of the interview and asked about participants' availability to do the research, with no pressure to participate. The process as described was that I would ask questions and the participants would answer these questions, or decide not to answer any questions posed. This process would be recorded and notes would be taken from the beginning of the interview. After this introduction and explanation, the conversation started with personal questions (such as what they do in their spare time; what are their hobbies; what is their favourite food), which helped build further rapport with participants, and helped ensure a good flow of conversation. After the participant and I were both settled, the interview questions started by asking the participant to introduce herself (i.e., age, marital status and educational level) and to

describe her experience of living with disability in Indonesia. After the participant's point of view was established, including her understanding of disability, I asked more specific questions regarding what the participant knew, wanted and hoped for from government policies affecting their rights when accessing health services. Subsequent questions were stimulated by the responses to previous questions intended to elicit further discussion about participants' daily experiences in accessing healthcare services. At the end of the interview, participants were welcome to add information that I had not specifically asked for, and to ask questions regarding the study. The participants seemed enthusiastic and responded positively to this invitation by asking questions about the usefulness of this study and some even asked for a copy of the results of the study. I closed the interview by thanking them for participating and further reminded participants of the gift or koha to be transferred via the SAPDA bank account. The average interview time was 50 minutes, with a range of 47 – 57 minutes. The women demonstrated no evidence of psychological distress during the interviews.

Nine participants were interviewed; SAPDA did not provide further participants. Validation and consistency were achieved by comparing and testing the themes that emerged from the interviewees' data. During the interview stage, the audio records were transferred, transcribed and saved as electronic data in a password-protected computer; the hard copy was saved in a locked filing drawer accessible only by me. This interview phase commenced in September 2015 and was completed in November 2015; it was structured around a list of questions geared to elicit responses and generate discussion to help the researcher to gain information vital to formulating

effective policies (**Appendix I**) according to the study's objectives mentioned in Chapter 1 (Introduction). The aim was to add new knowledge regarding influences on 'gender and disability'; to explore and describe the understanding and experiences of women with disabilities in accessing healthcare services; and to reflect on how these impressions are likely to affect their use of health services in the future. Data collection involved audio recording and note-taking during the interview, which assisted data management and analysis, and supported accurate transcriptions of the interviews. Use of an audio-recorder maintained the robustness of the data when analysing the information from the interviews by ensuring women's responses were represented in their original form. The recordings were backed up on CD/USB/hard drive. These copies were stored in a separate location from the original and will be kept for five years in locked storage in the School of Health Sciences, at the University of Canterbury. Thereafter this material will be erased and destroyed.

Following the provision of informed consent, participants' personal identifying details were coded to maintain confidentiality. Identifying factors such as names, addresses, and interview location were replaced with new code identifications (pseudonyms). This new identification was used in transcriptions, note taking, audio, and analysis software. On paper, transcripts and notes that contained original identification and identifying details were covered with permanent black marker. As for audio recording, editing for anonymization is difficult; therefore, limited access to the audio information folder was ensured. Both paper and audio files were kept in a password-protected folder on a secure computer, only accessed by the researcher.

The informal interviews averaged fifty minutes in duration, ranging from 47 minutes to 57 minutes. Follow-up interviews were sometimes required during analysis to clarify information. These were undertaken by phone.

3.3 Data analysis

3.3.1 Data analysis process

Because the participants' experiences were vital to this study, thematic analysis was used for data analysis and interpretation. Thematic analysis was used to examine and analyse the key information gathered from the data, and then to interpret and sort that data into themes (Vaismoradi, Turunen, & Bondas, 2013). This is a suitable analytical method because it identifies the key point, which in this study was to understand the use of certain healthcare services by women with disabilities. Thematic analysis is compatible with the feminist constructivist methodology mentioned previously. The constructivist perspective believes that society is responsible for the construction-deconstruction of beliefs and biases in any aspect of social life, including human relationships, gender dichotomy and individual experiences (Locher & Prügl, 2001). To assist the construction-deconstruction process, themes gained from a thematic analysis process can emphasize individual experiences. Data gained in this way can then be used to demonstrate the interaction of the factors that create the phenomenon under investigation.

A researcher must deconstruct established systems and incorporate this information with the data obtained, then interpret its consistency based on existing theories and data. A researcher must understand the participants' narratives, filter the

information subjectively for coding rather than calculating frequencies, and place the created themes into common groups. Themes that emerge from this analysis are then re-grouped to create patterns. This is achieved through a deep understanding of the conversation. By checking the consistency between data and existing knowledge, the direct description of the study can be used to provide key themes in relation to the research question and the data. This approach is concordant with Braun and Clarke's (2006) suggestion that thematic analysis is an effective tool to produce intensive, rich data. The analytical process looks only at the information gleaned, rather than taking a latent approach, to ensure the accuracy of the rich and detailed data obtained.

3.3.2 Transcription

Before data analysis began, the data was tested by cross-checking it with the participants, who were encouraged to listen to the recordings and read the transcriptions. Participants were asked to make any corrections they felt necessary, at which point they could add further information or delete information from the transcription. The transcription process is an important part of the analysis process in interpreting information shared by participants (Oliver, Serovich, & Mason, 2005). Verbatim transcriptions help to produce precise information, as intended by participants. Transcription from audio recordings to written transcripts used the software NVivo (NVivo, 2014). NVivo is useful in helping to organize and analyse audio interviews, transcriptions and notes. To maintain confidentiality no uploaded data was saved to the NVivo website, only to the software on the computer used for transcription. This maintained the file's privacy by avoiding the data being saved to the

NVivo server. This program is easy to pause, rewind and fast-forward and allows the transcription to be written on the same screen, which improves the transcription process. The audio speed was set to three times slower than the original speech for transcribing the word file and this ensured that there were no questionable statements requiring clarification. Transcription was verbatim, without modification, to ensure meanings did not change and that no researcher bias was created when entering the data (Chadwick et al., 2008).

Cross-language challenges, when translating from Indonesian into the English language, lie with the translation method, the translator, and the maintenance of data trustworthiness (Al-Amer et al., 2015). The translation methods used in this study were verbatim and semantic, with no interpretation or paraphrasing done to preserve the participants' original meaning. During the translation process, difficulties encountered included finding equivalent jargon terms in Indonesian and English, and dealing with differences in tenses, prepositions, and grammatical structures. The transcription and translation was done by me. With my ability in the Indonesian language and familiarity with health care phenomena I could perceive meaning in the data in context when writing the report and thus maintain trustworthiness in the data.

After finishing the transcription process, I re-checked the post-transcription records to avoid inaccurate or ambiguous punctuation, spelling or typing errors and any misinterpretation that could affect the authenticity of the body of data (Easton, McComish, & Greenberg, 2000). Bahasa Indonesian is my native language, thus there were no obstacles to translating the transcripts into English. The transcription process

was carried out in a quiet area, using headphones to avoid distraction and avoid others overhearing the recordings. After the audio data was transcribed, the analysis process began and was completed in six stages. Data was organised and managed manually in producing hard copies of the transcripts and coding them. The framework used was inductive thematic analysis: the raw data collected was used to create themes and connect the relationships between the themes with the findings, allowing flexibility in the management of the information (Thomas, 2006; Braun & Clarke, 2006). The next step used a semantic approach, which focused on explicit meaning and its preservation (Braun & Clarke, 2006).

3.3.3 Thematic analysis procedure

The thematic analysis used for this study has been found to be effective in answering research questions because it looks at the themes derived from the data and their relationship to each other in a systematic manner (Braun & Clarke, 2006; Vaismoradi, Turunen, & Bondas, 2013). It is a flexible method that reflects reality via participants' own rich descriptions (Braun & Clarke, 2006). To determine a relationship between interview questions and research objectives, Braun and Clarke (2006) devised a six-stage procedure for thematic analysis, as described below.

1) Familiarisation with the data

The purpose of familiarisation with the data is to classify initial common experiences, individual events, and actions as general themes, clues and ideas. This is achieved by reading and listening to the data, highlighting themes, points, keywords, and emphasizing the experiences revealed in each participant's transcript.

2) Generating initial codes

After the general themes are identified, initial codes can be processed. Statements or quotes from the interviews that have similarity or relevancy are grouped under the same codes until they form patterns. This stage should be clear from the researcher's *a priori* knowledge. In my investigation, using NVivo software, the statements were colour-coded into lists with similar meanings to simplify the organization of the data. If required, additional notes and information could be added. This process was conducted repeatedly and continuously until clear patterns emerged.

3) Searching for patterns

The lists of codes from stage two are grouped into themes using a semantic approach, which searches for explicit meanings, commonalities, and differences of meanings. Themes are created from the surface meaning, using nothing outside of what the participants have said. The themes can then be determined by manually creating a table of codes, and moving these codes around to organise and categorise them into suitable themes. During the analysis process, once relevant information has been categorized into themes and sub-themes, these can be used to create a mind-map diagram. Mind maps are used because they provide ways to organize and connect themes with keywords, and provide a visual aid to understanding the “hierarchal” and “multidimensional” levels of a relationship (Wheeldon & Ahlberg, 2011, p.15).

4) Reviewing themes

Reviewing themes involves checking that the themes are consistent with the raw data and is achieved by determining whether some themes can be linked with other themes, to either create new themes or eliminate unnecessary ones. In my study, a dictionary was used to find synonyms to determine key codes in order to identify the new word being sought and to ensure that no raw data was omitted. It was a back-and-forth process between codes and transcripts. Using Braun and Clarke's (2006) review process, final themes are re-checked against transcription data to ensure the final themes provide an accurate representation of the participants' experiences. The re-checked final themes are then inserted into an updated mind map.

5) Defining and naming themes

This stage is a refinement of the analysis, which establishes the trustworthiness of the proposed themes and sub-themes, supported in my research by consultation with supervisors. After the themes and sub-themes are organised, they are checked again to ensure that this aligns with the participants' experiences and their descriptions of their experiences in accessing healthcare services.

6) Producing the reports

Statements and quotations from the raw data are included, along with an analysis of the themes, as supportive data in a final report.

3.4 Rigour in qualitative research

According to Ary et al. (2013), qualitative research is an important research method. Like quantitative research, qualitative research has certain measurement

criteria to ensure the trustworthiness of the research. According to Lincoln and Guba (1985), the philosophical issues for trustworthiness in qualitative research are credibility, transferability, dependability, and conformability.

Credibility and conformability address whether the data and its interpretation of the research explain the reality being investigated. The results are based only on the raw data and a researcher ought not to interfere with it by inserting personal notes or comments (Major and Savin-Baden, 2012; Shenton, 2004). During the study process, I needed to have confidence in my observations, interpretations, and conclusions and I thus needed to do a reflective analysis. My personal background, values, perceptions, feelings, and understandings could have undesirably influenced the whole project. To eliminate these influences I carefully used the reflective process to guide and understand how my own beliefs influenced my research process. This was achieved by listing ideas, thoughts, or comments that arose as a personal reflection before and after the interview process, during the transcription process and the analysis process. I avoided incorporating those influences into my data and focused only on the interview results. However, subjectivity is unavoidable, and on some level will influence the analytical process. The feminist literature suggests that during the analysis, researchers should make explicit their own processes by reflecting on interview conversations with their own notes. During the analysis, the researcher must incorporate the participant's involvement and be reflective in the process (Wasserfall, 1993; van Staple, 2014; Wilkinson, 1988). Both parties' personal beliefs and reflections in the analysis process will shape and influence the revealing of knowledge.

My medical background supported me in understanding the healthcare services. However, gaps in my knowledge regarding the provision of health services for women with disabilities were filled by the participants' information. The fact that in the past the participants and I were in opposite positions in healthcare services, but were now aligned in this study supports the credibility of the research. With some level of knowledge about the healthcare system and services, I needed to caution myself as it could have influenced my personal beliefs. I also reflected on the fact that although I am a woman, I do not have a disability. However, I have knowledge of disability in women through personal experiences in which I served them in the past in my capacity as a medical practitioner. I also shared detailed information with participants about myself, telling them the reason this topic caught my interest, and I stated that my knowledge about disability was insufficient compared to theirs (the participants) as the experts.

Deferring to participants as the experts was demonstrated by asking the participants to check the interview data. I offered the participants the opportunity to read the transcripts, make corrections and offer suggestions (Ary et al., 2013; Major and Savin-Baden, 2012). Each piece of information provided by the participants supported my understanding of what was happening in their world.

My personal bias was minimised by checking and rechecking the interview data using an inductive audit trail, which provides a complete documentation process of how I read, analysed, and interpreted the raw data to generate the findings. During the data analysis, I linked it with my personal notes. This process critiqued the research by encouraging me to question my own process: did I ask the right questions? Did I listen

and interpret them correctly? And did my personal background affect the data gathering process? This ensured that a high standard of procedures was maintained, preserving the purity of the research according to its purpose. This confirmed that the findings were from the raw interview data and were not influenced by my personal beliefs (Shenton, 2004). Avoidance of the inclusion of personal reflections ensures the maintenance of a factual investigation.

Alongside the documentation, I used verification techniques and reflective comments to control for any potential bias (Ary et al., 2013). I involved the participants in reading the transcripts, findings, and themes. They were asked to confirm whether my analysis and interpretation represented their experiences. The intention of this process was to allow other researchers using the same data to come to the same conclusions and to show that I, as the researcher, was committed to eliminating any intentional or unintentional bias during the analytical process.

Transferability and dependability are closely related in a qualitative study. Transferability and dependability occur when the same method, context, and types of participants are used in other settings, the findings of which will be consistent, with minor variations in investigation results, when compared with the current study (Major and Savin-Baden, 2012; Ary et al., 2013). Even though the findings in this study varied from other similar studies, they were still in line with the overall findings of those studies. The findings were also consistent with the theoretical framework that was used as a guide during the study process. There are three potential negative impacts – the adequacy of the descriptions elicited, the similarity of responses, and the reactivity of

respondents (Ary et al., 2013). Providing a detailed methodology for the study, enabling it to be replicated by another researcher, is important.

I also carefully employed a reflective process and statements during the procedure and explained my involvement in the study both before the interview process and throughout the analysis chapter. I mentioned any limitations and weaknesses of the study in order to validate the results and in order for the findings to be transferable or applicable in a variety of contexts.

The next chapter presents the study's findings.

Chapter Four:

Findings

This chapter reports on participant's experiences in their daily lives and in accessing healthcare services as a person with disabilities. It highlights their impressions of current programs that affect their access to healthcare, and their expectations and hopes for future improvements. The analysis identified three broad categories: healthcare services, disabled women's communities, and the relationship between healthcare services and women with disabilities, from which eight themes were generated providing insight into disabled women's experiences of healthcare services. The objective of this chapter is to disclose the stories told by participants in a profound and systematic way.

4.1 The characteristics of participants

Nine female participants with varying disabilities from Yogyakarta in central Java were recruited exclusively through SAPDA. Their characteristics are presented in **Table 3**. They were aged between 25 to 45 years old (see **Table 3** for breakdown of the ages). Half of the participants acquired their disabilities at an early age due to polio. Only one woman experienced a congenital disability and the rest were impaired as a result of traffic accidents at later ages. The majority of participants (seven women) were married with an average two children. All of the participants graduated from high school, and three completed an undergraduate degree. Two participants reported

being unemployed, while the others worked as office administrators, and owned a small grocery shop.

Table 3: Participants characteristics information

Pseudonym	Age	Marital status	Educational Level	Ethnicity	Disability-Cause	Interview Length
1. Amelia	28	Married	Bachelors	Javanese	Right leg amputee-Accident 1998 (age 11)	47:03 minutes
2. Bella	39	Married	High school	Javanese	Limp-Diseases (Polio) 1982 (age 6)	50:04 minutes
3. Chloe	33	Single	High school	Javanese	Cleft lip/palate-Congenital	49:21 minutes
4. Donna	45	Single	Bachelors	Javanese	Limp-Diseases (Polio) 1972 (age 2.5)	51:44 minutes
5. Eva	38	Married	Bachelors	Batak	Left hand amputee-Accident 1984 (age 7)	53:02 minutes
6. Frances	41	Married	High school	Javanese	Paraplegic-Accident 1997 (age 23)	48:23 minutes
7. Grace	34	Married	High school	Javanese	Right leg amputee-Accident 2005 (age 24)	49:13 minutes
8. Hillary	42	Married	High school	Javanese	Limp- Diseases (Polio) 1978 (age 5)	57:22 minutes
9. Imelda	33	Married	High school	Javanese	Limp- Diseases (Polio) 1985 (age 3)	52:41 minutes

* Javanese: native Indonesian from Java.

* Batak: native Indonesian from North Sumatra.

4.2 Themes

The analysis identified the gaps in healthcare provision, barriers to access the healthcare services, and pointed out some of the individual expectations toward healthcare system based on existing programs and plans. Not only does it reveal the experiences of the individuals' interviews, but it also demonstrates how these experiences influenced the participants to manage their disability.

The thematic analysis identified eight themes:

- 1) An inadequate healthcare system and services for women with disabilities
- 2) Stereotyping, stigma, and discrimination regarding disabilities from healthcare

providers

- 3) Accessing health and disability information
- 4) Physical barriers leading to the exclusiveness and isolation from society
- 5) Attitudinal barriers that lead to segregation from community
- 6) Challenges in women with disabilities' life: desire for normality and to be accepted
- 7) Difficulties creating a positive image as a self-reliant, resilient, and accomplished individual
- 8) Self-solution: what women with disabilities learned from their disabilities

4.2.1 An inadequate healthcare system and services for women with disabilities

The majority of participants reported that they had negative experiences when receiving healthcare services, most particularly when they lived in a rural area. The interviews showed that participants felt the healthcare services received had ignored the fact that they had disabilities. As the interviews were conducted with women who resided in the Yogyakarta city area, the interviews refer to Yogyakarta's governmental programs and policies, which may or may not reflect the policies of central government. Yogyakarta's local government recognises the needs of women with disabilities, having produced three policy documents addressing 'disability' and 'women'. The provisions in these policies cover public access, inclusive education, and fulfilment of the rights of the person with disabilities.

Evidence of progress of the disability program by the government was revealed by one participant, Hillary. Before moving to Yogyakarta city (Java island), Hillary lived in a rural area in Lampung (Sumatera island). She recognized differences in the

distribution of health information for disabled people between the two cities. She noted:

“Before I moved here (Yogyakarta) one and a half years ago, I realised that information of health services [sic] was not widespread. If you did not join a disabled community or association, you would not get up to date information regarding free health services. For example, if there is free surgery for cleft lip, he/she would not get the information, then he/she will miss the opportunity.”

For a footnote, the sentences structures in participants’ quotes reflect the nuances of the Indonesian language, which, for example, does not recognise distinct tenses and prepositions.

Eva, who has lived in Yogyakarta all her life, similarly noted the progressiveness of healthcare programs in Yogyakarta. As an occasional volunteer for SADPA, Eva had noted that the needs of disabled women appeared to be taken into consideration in the delivery of services:

“Now with BPJS [Badan Penyelenggara Jaminan Sosial-Healthcare Insurance by Healthcare and Social Security Agency] and government awareness programs for disabled people, it seems the health workers are more attentive and care. They also improved the program, like they [the government] try to close the distance between the service and the location of the disabled person. If I am not mistaken they will launch comprehensive programs so patients do not need to come for treatment repeatedly for one disease.”

Bella had contracted polio as an infant. Since then she suffered two significant accidents (she had fallen when walking with a walking stick, and had also suffered a motorbike accident), which required regular use of health services. Regarding free healthcare, Bella commented on how flexibility and options had improved her experience of healthcare:

“The BPJS really eased my burden. I have had back pain for the last two years.

The doctor said I should have surgery, but it would be 50:50 chances to heal [sic]. So I said “no” to the surgery; instead, I chose physiotherapy twice a week.

It works fine for my pain. And I get it for free.”

The women’s opinions indicate that local government views persons with disabilities as individuals with the potential to improve their own condition through proper assistance. This kind of view leads to the correct programs and policies being developed according to the disabilities need; which is demonstrated from the interviews.

Despite satisfaction with wider access to services, participants stressed that progress to improve the facilities and the organisation of services for disabled women must continue. Imelda elaborated on access to healthcare:

“Maybe the government should modify the examination bed so it is not too high.

It is not that I requested special treatment, but it is for comfort when having an examination. Please improve this access for disabled.”

Frances commented on the organisation of healthcare within government departments:

“Why are we grouped with the elderly? We have different diseases. It could be a woman with disability who is pregnant; old people do not get pregnant. They should be separated.”

Central Government has grouped the elderly and disabled populations together because both are seen as disadvantaged and vulnerable groups. To simplify the provision of healthcare services, they are served under one roof. But, as observed by Frances, the two groups have different health problems that need to be treated differently by different specialists. Frances also opined that healthcare services for women with disabilities could be closer to home:

“And especially for women, there should be home-care to reach those who cannot access the services.”

Participants’ reports indicate that the Yogyakarta government’s programs and policies see ‘the disabled’ as a group of individuals who have the ability and potential for independence when provided with the right tools and when facilitated to integrate into society. The government acknowledges that it ought to help persons with disabilities gain independence to fulfil the rights of the person with disability, as identified in legislation No.47. The existing government programs are based on this legislation, which recommends providing opportunities for disabled communities to participate in society – and acknowledges the involvement of the disabilities sector as stakeholders. Its objective is for the government to develop the right tools to advance the objectives of integrating the people with disabilities into communities (UU No.47, 2012).

4.2.2 Stereotyping, stigma, and discrimination regarding disabilities from healthcare providers

In Indonesia, there are two distinct sectors of healthcare provision: government and private providers. Both are regulated to provide free healthcare services to everyone funded by the government. In reference to health workers' attitudes and facilities, most participants did not differentiate between the services provided by the two sectors. They were satisfied with the friendly service and free healthcare. Most participants also mentioned that in the capital city, the service was satisfactory and they encountered less discrimination due to disability. Despite positive overall experiences, participants acknowledged instances of discrimination and stigma. Regarding health workers' attitudes, Grace spoke of a bad experience of someone she knew from her village who had been subject to enforced sterilisation.

Grace: *"...there is a counselling program: as for service there is a thing that I do not like.*

It was enforced sterilisation toward [sic] certain disabled women (with a cognitive disability). If it is urgent I can accept it, even it is difficult to accept. But if it is not urgent, it is her right to have children."

Me: *"What do you mean by 'urgent'?"*

Grace: *"If the woman could die if not sterilised, I could support that. But if it because [sic] her family order her to be sterilised because of her disability I do not agree."*

Bella spoke of a similar incident when she delivered her second child two years ago:

"The nurse said this to me: 'Why would you have more children when you even have difficulty walking. Why don't you get sterilised?'"

She contrasted the nurse's attitude with her obstetrician who never made a negative comment. He was considered to be attentive, caring, and communicative throughout the pregnancy and delivery. The nurse's misconceptions of motherhood among women with disabilities reflects a common negative perspective that is consistent with the literature i.e. misconception that women with disabilities are asexual, and therefore ineligible or incapable of motherhood.

Another negative experience was relayed by Frances. Encouraged to be a compliant patient, Frances received a negative comment when she'd had an accident:

"One time I had an accident. I was really hurt and I groaned because it was very painful. The nurse told me to be quiet. Why can't I groan? It was really painful."

Such mind-sets are not the only concern. From one participant's point of view, there was a sense of health workers' reluctance and ignorance to interact with women with disabilities. This creates a communication gap when providing and receiving healthcare services and this can further disable patients:

Amelia: *"It happened to me a couple of times when I was in a wheelchair. They saw me coming, having difficulties to enter [sic] the hospital, but they never offered me help. I think they were reluctant to offer because I could be angry at the offer of help. So they were confused about what to do when they saw someone who is disabled. If they offer the help in a normal tone and acknowledge that the disabled person is having difficulties it will not be an offensive offer. And I think to educate the health worker on how to offer help to disabled people is a good*

idea. And I have other thoughts for providing service for people who are deaf or blind; maybe hospitals could provide a special liaison person to meet this need."

In summary, healthcare providers require a better understanding of the issues that are pertinent to the women with disabilities, possibly through the use of appropriate content in the curriculum of their training and continuing professional education, with an aim to improve communication between health workers and persons with disabilities. Introducing additional assistance or resources to bridge communication gaps could be one strategy, as mentioned by one of the participants.

4.2.3 Accessing health and disability information

Regarding access to information about their health, participants revealed that as a first source they would ask their family. Most participants received information and advice to manage their disabilities and health from mothers and family members who had employment in health. Closest family and friends often provide educational information and guidance but accessible medical professionals (including friends) were also a popular first call for information, as the following participants explain:

Chloe: *"Well, because I rent a room and have many friends there, I will ask them first before I go to the doctor."*

Imelda: *"My mother is pretty knowledgeable. When I ask about health most of the time she will have the answer."*

Grace: *"I will just call or text my regular doctor. He is very nice and will respond quickly to my questions."*

Eva: *"I have relatives who are doctors and nurses, so I ask them questions about health. They are pretty helpful."*

Amelia: *"Before I go to a doctor, I will look up information about my symptoms on the internet. If it is not dangerous, I probably will not seek the help."*

Before free health coverage from the government was implemented, the health system was funded by out-of-pocket payments. A patient would pay for health provision with his or her own money. Financial problems could inhibit persons with disabilities from seeking healthcare and participants often sought alternative sources of information prior to seeking formal healthcare.

Frances: *"We never talked about disability at school. Even in the physical exercise class we never talked about it, we'd just talk about normal people's health."*

Bella: *"I don't think people outside my family understand about disability. Either they hesitate or they don't care about it (disability)."*

The pattern derived from the interviews demonstrated a reluctance to engage with formal healthcare provision as a first step when ill. Instead, health information and core understanding of disabilities come from the woman with disabilities' closest family; however, the content of this information was not discussed.

4.2.4 Physical barriers leading to the exclusion and isolation from society

The participants revealed that physical barriers restrict integration into society. Throughout the interview, one recurring problem mentioned by most participants is access to move between places (e.g. from the home to a health service as the destination, and from one health service to another health service) and access to enter

the destination buildings/area. They mentioned that non-accommodating infrastructure discouraged them from going places. Those who required crutches or wheel chairs noted the access to the hospital as a concern, such as the slippery floor and/or lack of an elevator. However, the physical barriers mentioned were not limited to healthcare access. Donna seemed satisfied with the healthcare services she received but commented on access:

“For me, the services are not an issue. For me, it depends on the building. Like if the floor is slippery or not. That is all I look for because if it is slippery I could slide and fall. If it is not slippery I will be fine. As for the medical examination also I have no problems. Ohh...unless when the examination room is on the second floor and I have to take the stairs: that is a problem.”

Grace mentioned the physical challenges of transport to activities and access to the location in her daily life:

“I take a bus for my activities. The difficulty is in the whole process to reach my destination and back. There is no flat pavement to reach the bus stop from my house. And then, there are stairs at the bus [bus and station]. I have to pass that stairs [sic] to buy the ticket. And then, to enter and out of the bus, there is a gap. If I’m not careful, my crutches will slip into the gap. Another thing that could happen to me is I could be drag [sic] by the bus when the bus driver does not have the patience to let me enter in and out of the bus.”

She also identified the physical barriers that could keep her from leaving the house because either she needs assistance from a person, equipment, or facility to access a building:

“I like to be active, either with my friends or in my community. I think it is important for me to be able to access my destination. I do not want help from somebody each time I need to go somewhere.”

An alternative method to reach a destination was by taking a taxi or a ride from family members/friends to the destination. Interestingly, three of the participants also mentioned that rather than depending on others to go somewhere, they decided to learn how to ride a motorbike to make travelling easier. For example, Bella said: *“I cannot depend on others. Therefore, I insisted on learning how to ride a motorbike. And I did it.”*

The majority of participants agreed that the pedestrian path in Yogyakarta is narrow, un-level, and bumpy and as a result they reported that they chose to cancel or avoided the travel.

4.2.5 Attitudinal barriers that lead to segregation from community

According to the participants, negative attitudes and behaviour from society can lead disabled women to become isolated and reluctant to integrate into the community. They identified this experience to be common and significant. Throughout the interviews, it was revealed that in the city, women with disabilities were accepted and participants gave the general impression that they were not treated differently to the non-disabled. However, when discussing life in rural and remote areas, the

women's social circles and community still demonstrate a lack of knowledge about disabilities. Bella currently lives in the city but previously she resided in a rural area of Yogyakarta. She stated:

"One time I rode my motorbike (in Klaten, a small city outside Yogyakarta) and police caught me because I had no driving license but I was in the process of getting one. The Police said to me, 'You walk like that and you want to drive a motorbike?' And I said, 'Well I know how to ride a motorbike, why can't I have a license?'"

According to Link and Phelan (2001), stigmatisation is a labelling system, a result of an interrelation between politic, socio-economic, and culture of society itself. Further, society as the dominance and the non-stigmatized group has the authorisation to determine an individual worth. Individual differences like disability is an object of stigmatisation, separation and discrimination.

All participants demonstrated that at least once in their lives, they experienced negative treatment from society, outside their social circle.

Grace: *"I took a small bus like I normally do. I stopped the bus at the bus stop. I knew the driver saw me. But he did not stop to get me."*

Me: *"What do you think the reason he did that?"*

Grace: *"He had no patience, I will be really slow to get in and out. "*

Me: *"Do you still take the bus now? If you do, could you tell me about your other experiences?"*

Grace: *"When I took the big bus my common experience is nobody gives their seat for me. Either they pretend sleeping [sic] or playing [sic] with their phone."*

Me: *"How do you feel about it?"*

Grace: *"I feel sad, not that I want to be treated special. But the offer itself is nice. It feels like that I should not be on the bus. But, maybe I am too sensitive."*

Grace's experience outlines society's ignorance toward disability. The issue within the society is illustrated by the attitude to offer the seat to those who need. Similar feelings were pointed out by the other participants, such as Imelda describing her experience when she joined a neighbourhood activity:

"...[other people in the neighbourhood] comment like: 'What are you doing here?' 'Why don't you help out in other section, because we need to be fast here.' You know what they mean, right? I am slowing them down. I felt useless that time. "

Another example is from Frances. After her accident, she felt that her friends and neighbours talked less and less to her.

"After the accident, I lost my self-confidence. I could not do anything without help. I only lay in bed and feeling depressed. And one day I decided I couldn't live like this. So, I learned to sit and I prefer to sit on my front terrace watching my neighbours and friends passing by. After sometimes I realised not so many of them say hi to me anymore."

School, as the formal education provider, has not been accommodative to the disability and healthcare education. None of the participants mentioned school as the source of

information on disabilities. However, six of participants mentioned that schools are supportive of their physical disabilities and facilitated the needs of persons with disabilities by accommodating the disability.

Frances: *"We never talked about disability at school. Even in the physical exercise class we never talked about it, we'd just talk about normal people's health."*

Bella: *"I don't think people outside my family understand about disability. Either they hesitate or they don't care about it (disability)."*

The feelings and examples provided by participants showed that the negative attitudes (intentionally or not) could lead to discrimination and marginalisation. It impacts a person's life when their disability is seen as a disturbing anomaly by society. They feel unsupported and unaccepted, that could result in withdrawal from societal activities, which leads to personal negative behaviour and segregating themselves from society.

4.2.6 Challenges in women with disabilities' life: desire for normality and to be accepted

For all participants, being normal and feeling accepted just like non-disabled women was important. Social and emotional challenges are obstacles to be confident and self-reliant women. Part of the challenges women faced was having meaningful friends and a marital relationship. On a personal level, two participants stated that they had negative experiences in maintaining friendships and/or relationships with the non-disabled persons. Imelda noted that:

"I once had a relationship with a normal guy, but his family was against our relationship. They said: 'a lot of normal women, why [would] you choose her? Are you trying to make your parents mad?'"

One participant, Grace, who became disabled in adult life, mentioned that their friendship with non-disabled people changed since they had a disability.

"I had a lot of friends. But since my leg amputee, I sense that lots of them would not hang out with me anymore. They never tell me. But I assumed the reason was they will be ashamed seen by the public that they hang out with disabled."

The quotes above show that starting and maintaining a relationships and/or friendship is a challenge for women with disabilities. There was, however, no evidence of sexual violence or abandonment from a relationship. Seven of participants were married (with disabled or non-disabled partners) and have children and two remained single. All participants reported the desire to have a partner; however, they described accepting the likelihood that they will be single for the rest of their lives. For example, Chloe decided to quit looking for a man who could love her. She stated, *"no man wants me"* *"maybe I should look for women who will love me"*. Negative self-perception came from Chloe, who stated:

"...there is nothing I can do about it [her cleft lips/palate]. So I must accept it as it is. Sometimes I envy normal women. They could be pretty and confident, unlike me. No man wants to be with me because I am ugly."

Me: *"What do you think could improve your confidence?"*

Chloe: *“Having surgery for my lips will improve my confidence. But I have no money for it, and government health insurance will not pay for it because it is cosmetic.”*

Although only one person described negative self-perceptions, she suggested that physical appearance is important to be liked and accepted by the public. Three other – More positive participants – may be considered as prospective agents of change toward women with disabilities. The participants mentioned that, during their upbringing, they chose not to be friends with peers who had disabilities. In their opinion, those groups did not accept themselves. When asked why they did not make friends with other disabled people, they stated:

Donna: *“They seemed gloomy – just sat in the corner alone. I don’t want to be friends with that girl. They make themselves have no friends with that frowning face. Not until I graduated and became active in the disability organisation, then I made friends with them.”*

Hillary: *“I noticed a couple of disabled people I know showed an angry face when people stared at them. If it was me, I would look back at them and smile. By doing that, people will not be scared of me.”*

Participants described experiences or discrimination in which felt ignored, shame, and experienced low self-esteem. Regarding this feeling, Chloe noted that being *“having a complete physical is important”* and *“you’ve got to be a strong person when you have a disability”*. Through the interviews, assistance to manage the conflict and discrimination was perceived to be unavailable. Emotional support commonly came only from their closest family, especially one’s mother. The participants advice to deal

with discrimination was to *“ignore the insult”* (Bella), *“this disability is not your fault, don’t be ashamed”* (Donna), and *“if they don’t want to be your friends, find another one”* (Hillary).

It seems that all participants accepted their disability and have, in their own ways, overcome from the negative perceptions of others. None of the participants stated that society had an obligation to accept women with disabilities, but rather it is the women’s obligation to feel normal and fit in. Even though society plays an important role in the women’s acceptance of their own disability, it did not seem important enough to women with disabilities to raise this as a concern, implying either they received good support from society or they did not see it as a significant factor. Disability is uncommon, requiring normalisation and emotional support to fortify them against the negative comments and attitudes from peers and society, by giving the participants a feeling that they are cared for and thereby increasing their sense of self-worth and ability to cope. Women with disabilities acknowledge that they desire acceptance and integration. Combined with family support this could encourage empowerment of the women with disabilities.

4.2.7 Difficulties creating a positive image as a self-reliant, resilient, and an accomplished individual

Self-perception describes the inter-relationship between society, family, and friends and how they regard and treat women with disabilities. Women’s personal and social background influences their behaviours, opinions, and beliefs toward their disabilities. This theme represents the participants’ perspectives regarding their roles,

meaning and exploration of learning to live with a disability and discovering the meaning of their lives impacted by their beliefs. One of the participants suggested that too much accommodation can be negative for the disabled community itself; as stated by Eva:

“Having special treatment (for disabled people) becomes counterproductive to the disabled group itself. They become spoilt and then unable to be independent. There is too much expectation of ease and the facilitation of needs.”

And this is further illustrated by a comment from Hillary about a TV advertisement featuring persons with disabilities:

“You know that TV commercial about donations? They portray the beggar as someone who uses a crutch and asks for money in the street? It is embarrassing. Not all of us are begging for donations.”

Participants reflected that they have no role model who can portray women with disabilities as capable, strong, and independent.

Amelia: *“When I was at the university, I always tried to do best in class to prove that even though I only have one leg I can succeed in academic pursuits. And I did. I hung out with normal people with no issues. I don’t want people to pity me because of my leg.”*

Other participants did not mention the negative portrayal of the disabled community nor discuss the impact a positive role model could have for them. The majority of participants did not worry about the common portrayal of persons with disabilities as

weak and dependent. As long as their family and friends accepted them with their disabilities, it meant they understood that disabilities would not stop them from achieving their goals.

The impression of participants was that when people do not know a disabled person on a personal level succumbed to stereotyping encouraging negative stigma. Through stereotyping, women with disabilities are often considered weak and dependent on charity, and this affects the women with disabilities' own attitude toward their disabilities (Morris, 1989; Iglesias, 2004, as cited in INWWD, 2010). This stereotyping portrayal was described by Eva based on her experience during the school period. She noted:

“ I didn’t feel that teachers were supportive to [sic] my disability. They let me get away from [sic] the physical class. I know that they feel sorry for me. But no teachers ever ask me if I want to do it or not. Even the school counsellor never offered me support.”

Participants recalled negative experiences of the disability stereotyping during their time at school. Most of these experiences were a lack of support offered from the teachers and school counsellors. Only three of the nine participants confidently stated that they had escaped this stereotype through various pursuits — achieving higher education, gaining permanent employment, getting married, or through being active within a disabled association. However, these three women said they have their ups and downs facing those attitudinal challenges.

4.2.8 Self-solution: what women with disabilities learned from their disabilities

Frustration, desperation and teasing were common experiences among the participants that I interviewed. Rather than focussing on their frustrations and feeling helpless, some very positive statements emerged. Self-empowerment, education, and adapting to physical barriers are the main suggestions noted by the participants. Even though stigma was explored from participants' views of women with disabilities and society's image and treatment toward them, the participant's minimised differences between themselves and non-disabled.

Donna: *"This disability could stop or slow you down from doing something, even an easy thing. That forces me to think the other way and encourages me to do that thing."*

Amelia: *"I achieved better than my normal [non-disabled] friends during university. I graduated cum-laude. I also did not have difficulty getting a job and getting married. Now I am two months pregnant."*

Eva: *"I experienced constraints due to having only one hand, but I was determined that this would not be an obstacle for me in achieving my goal."*

They showed that they wanted positive changes in their lives. They could act as representatives of the women with disabilities, due to their intelligence, strong will, and sense of being respected and likeable women. All participants realised that they cannot hide their disability in a desire to be seen as normal by society. It was most noted from the participants that they must accept themselves with their disabilities, rather than asking society to accept them.

Most participants described it was important to disregard negative attitudes from others and focus on their own positive attitude.

Bella, who is married to the non-disabled man described:

“When we (she and her husband) walk together, people are sort of staring at us with the look.”

Me: *“What look?”*

Bella: *“You know...that my husband should be with a normal woman. I don’t like their look. It can be quite annoying.”*

Chloe: *“I cover my mouth when I laugh, so people won’t stare at my mouth.”*

Eva: *“When I use my artificial hand people won’t notice that it is a fake. But when they know it, they will give the uncomfortable look. Or feeling sorry face for me.”*

It appeared that each woman had her own method to feel normal. In their opinion, if they behave or look normal, society will accept them and they can fit in without being treated differently.

For these women, it would appear that a number of factors have contributed to their strength of personality and self-image. Family support, education, and individual personality seem to be closely linked to how well these women have met the challenges of negative social constructions of their disability. Throughout the interviews, it was evident that family was a core source of social support for acceptance. Family support may be emotional, physical, and educational that can encourage women with disabilities to develop self-esteem and pursue achievements that society may believe are unattainable goals for persons with disabilities. Almost all

participants identified the need for emotional support and described how social support affected their perception and acceptance of their disability. Eight participants emphasized that family support helps them to cope with their disabilities. Seven of nine participants had experienced disabilities since childhood. These participants spoke highly of their family supports and did not seek support from outside of the family members.

4.3 Summary of findings

This chapter classified the themes identified by Thematic Analysis and provided raw data through the women's reporting of their experiences under each of these themes. One of the key areas was the healthcare system and services for women with disabilities in relation to their disabilities. According to the participants, they did not experience major difficulties accessing services because of the improving awareness of disability in the capital city, Yogyakarta. The government's programs have in general, created a supportive atmosphere for people with disabilities, although some improvement of the physical accessibility of facilities is required.

The comments from the women demonstrate significantly different treatment and stigmatisation received from health workers in rural and remote areas compared to treatment received in the city. The majority of participants experienced positive support from friends or neighbours. Stigmatisation and negative identity are still current concerns from outside the participants' social circle, while the reality is that a lot of women with disabilities succeed in something. However, such achievements are rarely reported in the news. Participants in this study held a strong opinion that they

have no role model who could influence a change of people's opinions toward women with disabilities. Other key concerns include treatment of women with disabilities by health professionals and opportunities to make appropriate accommodations within healthcare settings. The majority of participants hope that government will fulfil the objectives of accessible facilities, facilitation of independence, increasing awareness of disability and positive appreciation towards women with disabilities.

Most participants also agreed that current access and societal attitudes continue to be seen to discriminate the disabled by being exclusionary. Thus, they tend to isolate the individual with the disability, rather than facilitate integration into the community. Also, such isolation encourages dependency rather than independence. Further, being seen as protecting the individual as a vulnerable person, opening access to activities can subvert opportunities for empowerment, encouragement, participation and equality. Strong family support plays an important role in enhancing women's self-perceptions, setting and achieving goals. Isolated women and those with unsupportive families appear to be more vulnerable. According to some participants, at a collective level as a community, disabled persons may be seen as protected, and they see this view as opportunities to overturn the negative into a positive image: individuals with empowerment, encouragement, and participation in pursuing equality with non-disabled.

This chapter provided the analysis from the themes, based on participants' reporting of experiences lending it a genuine voice. The discussion will explain each

theme and will explore the relationship and relevance of each to existing research, and how this thesis contributes to this field of study.

Chapter Five:

Discussion

Existing research found that women with disabilities still experience barriers in accessing healthcare services, however, there are limited studies regarding practice, program or policy to overcome these obstacles. Studies from Walsh-Gallagher et al. (2013), Tomlinson et al. (2009), and Amin et al. (2011) address these barriers in healthcare services. Given this lack of information, this study utilized a qualitative design to examine the daily challenges and experiences of women with disabilities in Indonesia, particularly as they access healthcare services. The objective of this chapter is to evaluate the study findings in light of the existing literature regarding healthcare services for women with disabilities. This chapter will analyse and compare disability policies in Indonesia (national) and consider the implications of the findings for participants at the Yogyakarta (local) level. The findings will inform recommendations for improving existing policy frameworks to enhance healthcare accessibility and address the needs identified by women in this study.

Secondary data was gathered to analyse the existing policies and to assess their effectiveness. That data associated with the study purpose was then used to support this study through a variety of online sources, e.g., the Ministry of Health's website, the Indonesian central agency of statistics, disability communities and non-governmental organisation websites, disability journals, the local government (Indonesian and Yogyakarta), the national library, and the parliamentary website. The results were

narrowed down based on the study's purposes to include only those related to access and rights for disabled people; health services; and specifically policies for women with disabilities. The progress and improvements of Indonesian national disability legislations, from 1945-2014, are listed chronologically in **Table 4** (national and local policies). From this list, it is apparent that legislation focusing specifically on women with disabilities is non-existent. This study endeavours to understand what obstructions stand in the way of developing and applying policies for the benefit of women with disabilities. The reminder of the policy discussion focuses on this issue.

Table 4. Legislation addressing disabilities in Indonesia 1945-2014

Legislation	Number/Year	Provisions
National Constitution	27,28 C, 28 D, 28 G, 28 H, 34/1945	Every citizen has the right to be protected and cared for by the government without discrimination.
Government regulation	68/1958	Ratification of the Convention on the Political Rights of Women
Decree	55/HUK/KEP/XI/79-1981	Minister of Social Affairs: implementation of social rehabilitation for persons with disabilities.
Decree	12/1981	Minister of Social Affairs: institutional rehabilitation for persons with disabilities.
Decree	66/1981	Governor of Jakarta on guidelines for accessibility in public facilities.
Decision	39/1983	Presidential decision on Coordination of Social Welfare for Disabled Persons.
Government regulation	7/1984	Ratification of Convention against All Forms of Discrimination against Women.
Agreement	0318/P/1984 45/1984	Minister of Education and Culture, Minister of Social Affairs, and Minister of Internal Affairs: coordination of assistance for children with disabilities.
Decree	002/U/1986	Minister of Education and Culture on Integrated Education for children with disabilities.
Law	72/1991	Special education for children/persons with disabilities.
Regulation	17/1991	Governor of Jakarta on Requirements of Accessibility and Equipment for persons with disabilities.
Decree	0491/U/1992	Minister of Education and Culture: special education.
Public Act	13/1992	Train Transportation: provision of special access

	23 /2007	for persons with disabilities.
Public Act	14/1992 22/2009	Traffic and land transportation: provision of special access for persons with disabilities.
Law	4/1997	Access for Disabled.
Law	43/1998	Promotions of Welfare of persons with disabilities.
Decree	468/1998 30 /2006	Minister of Public Work on the Technical Accessibility Requirement for Public Building and Its Environment
Law	39/1999	Basic human rights, including for those with disabilities.
Decree	71/1999	Minister of Transportation: access for persons with disabilities in facilities and transportation.
Decree	83/1999	Presidential decree on Coordinating Agency in Social Welfare Efforts for the Welfare of Persons with Disabilities.
Decree	104/1999	Minister of Health: medical rehabilitation.
Decree	205/1999	Minister for Manpower on Vocational Training and Job Placement for Persons with Disabilities.
Decree	140/2001	Governor of Jakarta Decree on Accessibility Team to promote the accessibility for Persons with Disabilities in Jakarta.
Law	23/2002	Child protection, including for those with disabilities.
Law	28/2002	Building construction, including access for those with disabilities.
Law	32/2002	Broadcasting: availability of sign language for deaf people.
Law	13/2003	Employment, including for those with disabilities.
Law	20/2003	Education, including for those with disabilities.
Decree	58/HUK/2003	Minister of Social Affairs on the Indonesian Braille programs.
Decree	96/HK/SE/2005	Minister of Social Affairs on the Implementation of National Plans of Action for People with Disabilities 2004-2013: for parents/family with children with disabilities and inclusion of women with disabilities involvement in community and development.
Decree	07/KEP/MENKO/KESRA/III/2005	Minister Coordination of Welfare on the Coordination of the Implementation of National Plans of Action for People with Disabilities 2004-2013: for parents/family with children with disabilities and inclusion of women with disabilities involvement in community and development.
Law	17/2008	Shipping: provide special access for persons with disabilities.
Law	1/2009	Airplane transportation: provide special access for persons with disabilities.
Law	10/2009	Tourism: specific facilities for travellers in public facilities.
Law	11/2009	Social affairs: social rehabilitation for those with disabilities, through institutional and non-institutional system.
Law	25/2009	Public Service, including special public service

		for those with disabilities.
Law	36/2009	Health, including for those with disabilities.
Decree	70/2009	Minister of Education and Culture: inclusive education
Decree	1/2010	Presidential decree on Accelerating Welfare Development through social security for disabilities families.
Government regulation	19/2011	Ratification of Convention on The Rights of Persons with Disabilities.
Regulation	25/2012	Ministry of Social Affairs: Standards of Social Rehabilitation of Persons with Disabilities by the Institute of Social Welfare
Regulation	1/2013	Ministry of Transportation: passenger standard service for hajj pilgrimage air transport including disabled
Regulation	14/2014	BNPB: management, Protection and Participation of Persons with Disabilities in Disaster Relief
Law	43/2014	To support the implementation of regulations No.6/2014 on the village area, which requires the empowerment of rural communities with planning and budgeting in favour and interests of the citizens with disability (article 127 paragraph 2).

Source: Data from the Republic of Indonesia Ministry of Health, the Ministry of Social Welfare, the Ministry of Transportation, and the Ministry of Public Work.

Armed with information regarding the introduction of legislation in Indonesia and Yogyakarta, the following sections revisit the key themes identified and outlined in the results section. The purpose is to consider these key themes in light of international studies, and local and national policies, and to identify pathways that might tangibly improve the lives of disabled women in Yogyakarta. Each qualitative theme will be discussed in turn.

5.1. Inadequate systems and governance to support disabled access to healthcare services

5.1.1. Collaboration: the key to improving policy

Women with disabilities in Indonesia are still marginalised, a factor evident in accessing healthcare services. Behind this reality are the lack of understanding of

disabilities and women, and poorly coordinated laws and legal frameworks in healthcare to facilitate the needs. However, the Indonesian government has produced a number of legislation changes in disability, to include women. Regardless of the numbers of new legislation, unsatisfactory implementation shows the lack of integration between systems and infrastructure, causing little improvement for the disabled population.

In relation to existing programs and policies for disabled people, the participants in this study mentioned the significant role of non-governmental organisations and their influence on disability programs. Bella, who occasionally volunteers in SAPDA explained that she recognized the knowledge she had gained through her affiliation with the disabled community. She believed the organisation listened to her need and her opinion. Another participant, Donna, identified the level of involvement of women with disabilities within the disabled community observing that it is higher in the city compared to the rural areas. According to her, this is a good approach for individual self-awareness and self-empowerment by being a productive individual despite one's disabilities. This information highlights the importance of involvement of women with disabilities' in disabled organisations or community. It also demonstrates that the women's involvement is highly valuable for the development of disability services.

In a study by Tomlinson et al. (2009), 82 stakeholders within the field of disability identified the challenges and made suggestions in accessing health to better accommodate their needs. Other than the removal of barriers, the results suggested

the coordination and linking of health systems with its stakeholders was required. It is important to understand the issue that has been identified, that involvement of people with disability to produce an accommodating policy or program is important (Tomlinson et al., 2009). Research has pointed out the importance of inclusion and intervention from the person with disabilities in the policy-making process to improve health policies, systems, and services, and this can be assisted by NGOs (Tomlinson et al., 2009; Amin et al., 2011; Valdez and Luzviminda, 1999). For example, when Indonesia joined the ratification of the Convention on the Rights of Persons with Disabilities; the regulation was drafted with coordination from disabled people's organisations, the human rights association, and the Ministry of Social Welfare (Himpunan Wanita Disabilitas Indonesia [HWDI], 2016).

However, women with disabilities are still challenged by political, socio-cultural, and infra-structural factors when seeking adequate healthcare services. They are also excluded from participating in the development of policies, programs, and specific healthcare services. The lack of availability of regulations and legal frameworks specific to healthcare services is an unmet political need that requires attention. The stories and experiences of women with disabilities must contribute to the formulation of policies if access to healthcare services is to improve for them.

With respect to political factors, this study highlighted that central and local government have created regulations regarding persons with disabilities, not only conforming to international disability frameworks but also developing independent national and local frameworks. Women with disabilities encounter hurdles when

accessing healthcare services. Government and healthcare providers are vital in accommodating the needs of disabled healthcare users. Based on this qualitative study's results, Yogyakarta's women would benefit most from participating in the development or implementation of policies and programs to address national healthcare coverage, access to facilities, non-governmental organisation services, and services for the elderly. Participation holds an important key - to be able to be part of the solution, agents of change, and to promote their rights (Gatjens, 2011; Hladki, 2008). Yet, this study did not find participants to be involved in consultation processes defining their concerns, nor in the intervention projects. However, it discovered from participants that disabled people's organizations and the government had already made inroads to integrate women with disabilities to participate in educating and promoting sex education and health as well as reproduction targeted toward adolescent females with disabilities. The government bureaucracy needs revision to be able to minimise the complications present in access to healthcare services.

5.1.2 Extreme financial burdens for those with disability

All participants reported the difficulties to gain access to healthcare services when confronted with an out-of-pocket payment system. Even though the majority of participants are employed, it appeared the priority of seeking healthcare was not at the top of the list, due to economic factors. Poverty makes householders reluctant to spend on health, due to the financial burden. According to Batavia and Beaulaurier (2001), people with disability have a tendency to be under financial stress due to the poverty cycle: low-income jobs due to disability, additional healthcare expenses due to disability,

and the high risk of unexpected medical expenses. However, the statistics regarding Indonesia's household expenditure on healthcare are inconsistent with the report from Batavia and Beaulaurier (2001). According to Doorslaer et al. (2007), the Indonesian's household reported that only 5% of households spent over 10% of their income on health. Through the findings of this study, participants positively stated that the out-of-pocket system has been replaced with the Indonesian healthcare social security program. The Indonesian government, in 2014, changed its national health programs by providing healthcare cover (BPJS- Badan Penyelenggara Jaminan Sosial). The Indonesian government is at the stage of shifting from an out-of-pocket system and are currently engineering social health insurance. This broad-ranging health cover, according to individual needs, has reduced boundaries to treatment and medication access, but the participants in this study were still constrained regarding aids for physical disabilities.

Before the national health cover scheme was introduced by the Indonesian government, the existing programs and policies had led to catastrophic financial burdens on those with disability, a direct result of the out-of-pocket system and the lack of government support to meet healthcare needs (WHO, 2005; Xu et al., 2007; Kroneneber & Barros, 2014; van Doorslaer et al., 2007). Surveys by Xu et al. (2007) in 89 countries suggested that 150 million people in the world experience catastrophic financial setbacks due to the costs of healthcare services. The critical point, tipping a family into abject poverty, is reached when a household spends 40% of its disposable income on healthcare. This study by Xu et al. (2007) also highlighted the obligations of

health policy architects to make healthcare accessible and recommended a change from out-of-pocket health systems to funded healthcare systems.

Challenges for those with a disability, in Indonesia, appeared to be solved through the national health scheme. However, the implementation of comprehensive coverage according to the needs of disabled people is still a formidable task.

Coordination between BPJS (Badan Penyelenggara Jaminan Sosial) stakeholders and agencies is needed to assess the availability of aids and make sure no people with disability are left without health coverage. Reliable data gathered through the cooperation of different agencies and stakeholders could be tapped into to gauge the effectiveness of the financial protection strategies and to inform enhanced policies.

5.1.3 Changing approach from medical model toward the social model

It is evident from the participants that the situation for people with disability in Indonesia is shifting from that based on the medical model toward a social model. All participants in this study, with physical disabilities, recognized the small shift in the government approach from a focus on the treatment of disability to a focus on the removal of barriers to participation. For instance, as mentioned by participants, the Yogyakarta government plans to provide a mobile healthcare service for people with disability. These programs are designed to be “one gate” and “door-to-door” services to individuals at a convenient location, according to their individual need. Such endeavours are intended to address barriers to access for visitors to healthcare services. The background of this proposed program, as suggested by participants, is based on the actual experiences of individuals’ with physical impairments, e.g., when muscular

weakness, deformities or amputations force a person to overcome the barriers when accessing healthcare services.

Social barriers according to the social model of disabilities refer to broad and varied difficulties and limitations in access to the environment (Garden, 2010; Nikora et al., 2014; Rothman, 2010; Baylies, 2002). This study's findings are consistent with the literature, suggesting that inclusive programs could reduce social barriers (Drainoni et al., 2006; Mitra & Sambamoorthi, 2009; Armstrong, Armstrong, & Barton, 2000).

Participants referred to the Yogyakarta government's changing approach; from a focus on rehabilitation and medication, it now places emphasis on education, awareness, and socialisation via cooperation and collaboration with stakeholders and disabled people's organizations. Participants suggested reasons for the shifting approach. Eva believed that the government identified women with disabilities as not weak, lazy or dependent individuals but rather that they could have jobs and earn an income. She also suggested that the government may listen to the requests of the disabled community that independence can be gained through easing or eliminating barriers. While Donna suggested that grassroots awareness and education about disability has successfully influenced government to review the existing programs and policy. However, participants failed to recognize the changing approach in the healthcare services environment. Instead, they found their own individual way to overcome the barriers they experienced and believed it worked for them.

The Yogyakarta government has focused on inclusive programs in its local planning and has been comparatively more responsive to disability, with superior efforts

and coordination of its approach to implementation. As participants' report, this indicates that the Yogyakarta government's programs and policies see people with disability as a group who have the potential for independence when facilitated with the right tools to assist them to integrate into society. The programs tend to maximise the disabled person's productivity by providing opportunities and by involving the disability sector as stakeholders. Thus, it has been demonstrated in Yogyakarta that the government can create the right tools to advance these objectives (UU No.47, 2012).

5.1.4 Participation in policy creation and strategic implementation through gender mainstreaming

This study revealed that marginalization of women with disabilities makes them invisible or unnoticed in policy development. Most of the participants in this study think they do not have the ability to influence disability programs, either through involvement in a policy process or acknowledgement as stakeholders. Only one participant believed how important it is for someone with disability to be able to be engaged in, to cooperate and collaborate with other stakeholders, and to involve women with disabilities in resolving problems across various issues. Participation holds an important key to contribute to intervention as agents of change, and provides a footing in influential positions, promoting the rights of people with disabilities. It was agreed by most of the participants that healthcare services they received had been focused mostly on the medical problems, rather than ask the disabled individual what was needed to compensate and improve the disabilities.

The literature review (Valdez & Luzviminda, 1999; Hladki, 2008; Tomlinson, 2009) suggested that stakeholders' participation will more accurately pinpoint the problems, strengths, and weaknesses of the current systems, and it is through the sharing of knowledge and evidence from the consumer that these matters can be acknowledged and addressed through informed planning for improvements and developments. Established legal frameworks in Indonesia encourage the strengthening of local and national cooperation with stakeholders and with disabled people's organizations in an effort to provide education about, awareness of, and socialisation of, people with disabilities (Norwich, 2008). It is crucial that the Indonesian government involve disabled women in addressing access for women with disabilities, but this is not limited to accessing health services. Participants were of the opinion that as women with disabilities, they view themselves as individuals who could live independently with appropriate supports in place. They have different abilities compared to other women and have different health concerns and needs compared to males and elderly folk. By developing optimal programs and policies according to the actual needs of people with disabilities, the poverty cycle could be curtailed in families in which there is a person with disability. Well-targeted interventions may provide greater opportunities for the women to be independent.

Utilization of gender mainstreaming is one of the many ways to ensure issues specific to women with disabilities' in Indonesia are visible and integrated into planning across a broad range of platforms. Through social construction and common perceptions, dominant groups influence the opinions of other groups of people who are

different to them. This results in the marginalization of the less dominant group. Based on a United Nations paper (2002), gender mainstreaming is a method used to identify the implications of a plan to manage men's and women's varied characteristics. This assessment is not limited to any type of government programs or policies. It targets gender differences and perspectives to enable prioritization of specific concerns in order to create equality. In this matter, the Indonesian government should utilise this facility to minimise disadvantages for women with disability. The comprehensive process of problem identification, planning, design, implementation, monitoring and evaluation of policies, programs and outcomes is especially crucial for women with disabilities due to the position as the most marginalised group in Indonesia and worldwide by highlighting the need to integrate gender dimensions into future planning (UN, 2002; Mitra, Posarac, & Vick, 2011; Mprah, Anafi, & Sekyere, 2014; Snyder, 1999). The integration of political, socio-cultural, and economic elements should result in outcomes that are equally beneficial for men and women. Gender mainstreaming integrated into the development of public policy is a way to deconstruct established social opinions toward gender and disability (Fonow & Cook, 2005; Acker, Barry, & Esseveld, 1983).

5.2 Barriers from healthcare providers influence access to the services

5.2.1 Influences on decision making for women with disabilities: access, attitude, and communication

In this study, the majority of participants drew attention to physical barriers such as the lack of available services and inaccessible facilities, referring to both the outside and inside of the buildings (e.g., the need for ramps, the need for a bigger toilet room).

Free healthcare services are unable to provide services to people with physical disabilities if they do not have accessible facilities, i.e., entry and exit from the building. The deterring influence of physical barriers on the decision-making of women with disabilities when considering whether to seek healthcare services has been studied with reports related to unsatisfactory feelings, unmet healthcare needs, and chronic disease (Iezzoni & O'Day, 2006; Goodman et al., 2007; Dudley & Emery, 2014; Hanson, Neuman, & Voris, 2003; Barry et al., 2009; Bradbury-Jones et al., 2015; Popplewell, Rechel, & Abel, 2014).

Transportation to healthcare services is also a problem. With inaccessible public transport, people with disabilities must hire private transportation to reach health centres. Escalated costs are introduced to rent private transportation to attend healthcare centres adding extra cost to the healthcare visits.

Two major problems were highlighted by participants in this study: first, inadequate infrastructure led to technical barriers in accessing healthcare services and, second, healthcare worker's attitudes discouraged service use. From existing literature, a physical barrier is any barrier from unfriendly staff to inaccessible buildings or transport, and unaccommodating examination procedures, a concern that is more frequently experienced by women with disabilities (Thierry, 2004; Turk, 2004; Devaney et al., 2014; Popplewell et al., 2014; Bradbury-Jones et al., 2015; Devaney, 2009).

Women with disabilities tend to frequent healthcare services for secondary conditions, according to Santiago and Coyle's (2002) study. Their study, conducted in Philadelphia, USA, with 170 women with physical disabilities aged between 21 to 65

years old, reported high incidences of failing to attend routine cancer screening appointments and of developing complications secondary to disabilities. Failure to attend was due to deficient access to healthcare facilities. This finding was similar to a study by Nosek and Howland (1997) where they found that women with disabilities are less likely to obtain preventive services compared to women without disabilities; this was said to be due to unsatisfactory access. When women with disabilities fail to access services to meet their healthcare needs, it can have a serious impact on their health and quality of life; it increases their risk of chronic diseases, a shorter life span and puts them more at risk of experiencing violence and abuse (Butler, 1990; Crepaldi et al., 2010; Bradbury-Jones et al., 2015). Previous studies (OHSU, 2008; Bradbury-Jones et al., 2015; Devaney et al., 2014; Nosek & Howland, 1997; INWWD, 2010) argued that for women with disabilities it is more likely that technical barriers prevent them from accessing healthcare services rather than social paradigms due to impairment. Women with disabilities' decision for not seeking a healthcare services may be influenced by particular reasons, e.g., the design of healthcare buildings, facilities' access, transportation, etc. rather than the communities' view and value of them as disabled individuals. This notion is consistent with the findings in this study, that the majority of participants experienced difficulties accessing examination beds and building facilities.

Prejudice and stereotyping within the healthcare sector toward women with disabilities were reported in this study. Such bias resulted in disrespectful treatment and a sense of disempowerment. This included suggestions by staff, 'not to get pregnant' or in staff not providing assistance to climb onto the examination bed. The latter caused

one participant to cancel a doctor's appointment. This discrimination remains an ongoing challenge faced by women with disabilities in Indonesia and prevents them from receiving their rights in healthcare and prevents them from being fully able to participate in society.

Lack of knowledge and presumptions leading to stereotyping of people with disabilities by healthcare workers was a major concern among participants. Stigmatisation from healthcare personnel can lead to poor services, inadequate treatment, refusal to provide the service, physical barriers, and procedural complications (Fiduccia & Wolfe, 1999). Effective communication between healthcare workers and consumers is yet another issue that needs to be discussed, rather than assuming that what is best for the majority of patients is adequate for all (Thomas & Curtis, 1997; Walsh-Gallagher et al., 2013). One example from their study was a participant's doctor who, rather than recruit someone to assist a new mother who had lost an arm to bathe her new-born, suggested that a professional bathe the child. In that study, the healthcare workers admitted to a lack of knowledge and reliance on presumptions and stereotyping of women with disabilities. The workers suggested more specific in-service education and training about disability was needed to overcome their lack of knowledge and to improve communication on the part of healthcare workers (Walsh-Gallagher et al., 2013). From this study, neither stigmatisation nor physical barriers to healthcare services were factors influencing the utilisation of healthcare services. This result is surprisingly different to what would be expected compared to the current literature. This initial study suggests that participants' positive characteristics as empowered and

independence women could influence a constructive image and awareness of women with disabilities. Further, physical barriers in accessing healthcare services considered as a minor difficulty could be overcome by addressing individual's strategy to perform an able action according to their disability. Existing studies confirmed that medical issues not related to disability prompted the use of healthcare, rather than the disability, lack of health insurance, poverty, low education or environmental concerns (Coyle & Santiago, 2002; Hosain & Chatterjee, 1998; Jeon, Kwon, & Kim, 2015).

5.3 Daily life challenges and negative experiences influence self-acceptance

5.3.1 Social elements and responses to social construction

Additional challenges to living with a disability are socio-cultural in nature and, in this study participants highlighted their unpleasant experiences when participating in society. Women with disabilities who grew up with certain social expectations and over-protection from their family may be more vulnerable to negative influences. These factors could affect mental health, personality, self-esteem and could result in a person withdrawing from social relationships (Agoramoorthy, 2011; Mji et al., 2009). In this present study, all participants had experienced negative treatment from society. There was another study by Buljevac, Majdak, & Leutar (2011) who looked into social elements of people with disabilities through the perspective of health workers' who care for people with disabilities in Croatia. The study identified two elements that contribute to negative treatment: a perception of being ill-treated by society - intrinsic (self-perception) and extrinsic (society) - for people with disabilities in the environment. The findings from Buljevac, Majdak, & Leutar (2011) agreed with a study by Taub,

MCLorg, & Fanflik (2004) who conducted interviews with 24 female students with physical disabilities. The researchers in that particular study suggested that women with disabilities overcompensate for the disability through other aspects of their lives. Most of the participants in this study showed consistency with the social management observed in the study by Taub, MCLorg, & Fanflik (2004), i.e., by relying on humour, cheerfulness, kindness, and normalisation for acceptance, the participants deflected attention away from their disability. Participants revealed that frustration, negative self-image, and low self-expectation were common experiences during adulthood.

This observation was also borne out in this present study. For example, Amelia emphasised her academic achievement despite her loss of one leg. Eva's opinion of special treatment for the disabled was that monetary compensations (charity, hand-outs, and subsidy) just added an extra barrier to being a productive member of society. Social constructions of disabled women often render them less powerful and less capable than non-disabled women, which are reported to create frustration for the affected women (Sen, Ostlin, & George, 2007). Amelia suggested her experiences in Yogyakarta city, where she lives now, were being treated 'normally' compared to her original community in a rural area. She assumed the different treatment received was because in her current city, the community got to know her personally and this interaction made her seem "human" to them.

5.3.2 Charity cases versus Independence image

This study's findings revealed that internal factors (personality) had more impact on the individual's perception of their own disability than external factors

(environment). Participants mentioned that they were teased or insulted because of their disabilities – and this was consistent with the literature but none of the participants specifically stated that external factors led them to downplay their disabilities.

Hillary highlighted the negative stigma of disability portrayed through advertisements for fundraisers, depicting disability as in need of charity, as though people with disability are incapable, and lacking a positive image. These attitudes may be re-constructed through education by correcting the perception toward women with disabilities and representing them positively as a thriving part of society (Hladki, 2008; Beckmann et al., 1989). Begum (1992) and Groce's (1997) studies confirmed that societal constructions influenced women's attitudes and decisions in certain aspects of their lives. Along with Begum (1992) and Groce's (1997) conclusion, this study reveals the similarity of the conclusion that daily encounters with society's oppression of them as women, and as disabled, have an effect on the thought processes of women with disabilities (Taub, MCLorg, & Fanflik, 2004).

5.4 Effect of physical and attitudinal barriers on exclusion and segregation

It was suggested from the findings in this study that social support was important, affecting the participants' concept of their disabilities. Social support holds an important key for individuals as a source of knowledge about health, as a means of improving self-esteem, and by influencing attitudes toward welfare, and in protection from self-harm. Social support outside the family was a critical contributor to many women's lives. Social connections include peers, schools, communities, regular health

workers, and extended family, as reflected in the findings of this study. When women with disabilities do not receive social support from their family, they tend to look for support from other groups (Duner, Nordstrom, & Skarsater, 2012).

Additionally, most of the participants in this study mentioned that school proved to be an inadequate source of support for health literacy. One of its responsibilities is to be attentive to the needs of the student, whether they have a disability or not (Ahmadi & Uhbiyati, 1991). Participants reported that school had not played the expected role in health education; accentuating the challenges for children with disability through isolation from physical activities and through the lack of adequate information. Frances' and Eva's experiences exaggerated their sense of isolation when school waived the requirement for them to participate in physical exercise even when they believed they could do it. Failure to integrate was also noted by Avramidis, Bayliss, & Burden (2000) study. Their study with 135 prospective trainee teachers in the United Kingdom demonstrated that teachers embraced inclusive education as a concept but were reluctant when the student with these needs was in their class. One of the drawbacks was that the felt they needed more knowledge of the disability and needed to be empowered with a strategy to manage the child's needs in the ordinary class (Avramidis, Bayliss, & Burden, 2000). This is consistent with the statement from participants in this study that school failed to fulfil its role as a responsible resource for dissemination of information by incorporating the knowledge of disability into health education classes. Therefore, it is important for schools to reassess their roles and systems by incorporating into the curriculum appropriate support for differently-abled students in

the school. This also is an area for further investigation in support of the integration process, to explore opportunities for better health education regarding disability.

5.4.1 The peer group - an overlooked resource within the group with or without disability

Peers are helpful in overcoming physical and attitudinal barriers for a disabled person. Peers in this study were divided into two groups: those with disability and those without disability. This finding in this study is in contrast with a previous study where it was suggested that peer support from people with the same condition played an important role in sharing information and experiences, and in self-belonging, and friendship (Stainback, Stainback, & Wilkinson, 1992; Byers-Lang & McCall, 1993; Scott & Doughty, 2012).

Donna and Hillary admitted that they were reluctant to make friends with peers who had a disability. They preferred the non-disabled group, describing them in terms such as *“friendlier”*, *“welcome gesture”*, and *“no pressure”*. They did not think that gathering with the group who had disabilities would help their integration into society. This finding suggested that peer support from disabled peers in the community was not a part of the social support the women with disabilities sought. Chloe however, suggested that adolescent females with disabilities ought to reach out to older women with disabilities for social support, especially when they did not receive adequate support or when there was a lack of health knowledge forthcoming from a family member. In her opinion *“... we (adult women with disabilities) are more beneficial to them. Because we could share our experiences during teenage years and they*

(adolescent female) *could relate to those experiences. We could also share our knowledge about disabilities and become someone they could look up to.*” She believed that a role model is important for encouragement and empowerment in dealing with disabilities and to reduce the risk of isolation, and such friendships could improve self-confidence.

It could be concluded in this study that supports mainly came from family. The family assisted the women with disabilities to behave “normally” in order to be accepted and to ease integration into society. Appropriate people need to be identified in helpful supportive relationships fostered within support systems to assist in developing self-acceptance and healthy well-being, particularly for the adolescent female (Foley et al., 2011).

5.5 Self-construction as women and as disabled

5.5.1 Intimate social support shapes self-construct

It is difficult, but necessary to address the different characteristics of women that contribute to the development of their identity, for example, their disability status, ethnicity, religion, etc. These roles and identities need to be considered and interpreted as central to shaping people’s experiences of the world. This study discovered that Yogyakarta is diverse culturally and the city, historically, had greater acceptance and awareness of disabilities, which has positively impacted on participants’ perceptions of themselves as ‘normal’.

In this study, all participants had a physical disability, the majority occurred during childhood. But, there was no evidence that disability type and time of onset influenced their sense of identity. However, across education levels, responses differed. The higher the education of participants, the richer and more detailed the responses they gave, especially when compared to high school degree participants. Existing disability studies lack understanding about the association between time or age of disability onset and individual background as these affect the wellbeing and social involvement of an individual (Nosek et al., 2003; Haider et al., 2014). It is, however, recognised that self-acceptance, self-cognition, and social isolation are influenced by age, gender, education, disability severity, cognitive ability, and social support producing positive or negative outcomes in arenas such as intimacy, employment and healthy behaviour (Nosek et al., 2003; Haider et al., 2014).

Nosek et al., (2003) specifically identified that a positive self-evaluation was strongly influenced by social support. The current study found that the women's self-acceptance intersected with previous themes, specifically, the level of social support from one's family and personal self-perceptions overshadowed the impact of the wider social environment. Participants who received support from family indicated they accepted their conditions and had greater levels of disability literacy. Literacy gained through the form of functional, structural, and instrumental support seems to contribute to an easier transition from non-disabled to 'disabled' status when coupled with a constructive personality (Holanda et al., 2015, Mehrotra, 2004; Schulz & Decker, 1985; Forouzan et al., 2013).

5.5.2 Gender, over-compensation, and empowerment - to be equal and able

Gender differences also affect women who are coping with their disabilities. It is known that women are more expressive and like to seek social support from friends and family, while men are less expressive and appear more accepting and prefer advice from professionals (Hoffmann & Tarzian, 2001; Duner, Nordstrom, & Skarsater, 2012). This study also found its female participants gained their support and health literacy from closest family members despite the unknown validity and reliability of information. They expressed their frustration regarding limited information about their disabilities. The majority of the women were frustrated at their lack of access to information growing up and believed informal discussions and shared experiences about disability would be beneficial. Other than sharing knowledge, it would enable them to understand their desire for normality and acceptance, as part of their development of their personal identity as mentioned by participants.

Each individual's experience is different and influenced by individual backgrounds and multiple roles as an individual. Individuality shapes the level of self-reliance and accomplishments. Individuals, including women with disabilities in this study, have the ability to overcompensate and empower their disabilities, leading them toward accomplishment. Self-construction corresponds to self-identity: appreciation of self, acceptance of their bodies, and not being embarrassed by physical impairment (Johnstone, 2004). Overcompensating and empowerment are attitudes that act as a mechanism for someone experiencing disability to embrace their new identity by being proud of their disabilities. Bearing their disability, they believe they can offer something

positive rather than focus on their 'disabled' status. Participants who fall into this category succeeded in recognizing their limitations and rejected the societal efforts for those with disabilities to conform, and found their own opportunities, thus fulfilling their own expectations, rather than society's. They managed to put those pressures aside without hiding their disabilities and treated themselves as equal and able-bodied people. This is a heart-warming outcome for some and demonstrates what is possible given the right circumstances

5.6 Strength and limitations of the study

Due to time constraints of the study, the interview process for data collection was completed within three months of the one-year thesis programme.

Preliminary enquiries resulted in low response rates and low allocation of resources from disability associations in Indonesia preventing the study from including all provinces, thus this study focuses on one province, that is, Yogyakarta in Central Java. Eight disability associations in Jakarta, Bandung, and Yogyakarta were invited to support this study. Six did not respond, including one returned envelope that was unopened. Two associations agreed to conduct this study but one of these offered no response to my follow-up communication, leaving only one association, SAPDA who supported the study.

Without representation from other provinces, disability associations and participants, the diversity of ethnicity and disabilities in Indonesia was not well represented in this study. There was a risk that the results of this study could be inappropriately transferred into the broader category of women with disabilities. As a

purposive sampling, this study relied on SAPDA's decisions and its influence in choosing and recommending the participants, which was based on the inclusion criteria provided by the researcher. Participants from urban, rural, and remote areas were included. The rural and remote area access presented difficulties for personal visits and/or phone contact. Remote areas were difficult to access due to unclear addresses and intermittent cell-phone signals, which interrupted the interview process.

The institution supporting the study, SAPDA, although they were willing to support the project had little time to commit to their original agreement. During this study, they were busy with other projects, the development of a Woman with Disability Crisis Centre (WDCC), which will deliver the legal procedure or mechanism for dealing with violence toward women with disabilities, and it also will provide training on reproductive health for adolescent females with disabilities to reduce sexual violence. Due to these diversions, the number of participants for this study did not reach the expected for data saturation.

Although this study acknowledges the existence of various types of disabilities, it did not discuss, nor analyse, the influence of different disabilities on women with disabilities. The participants' interaction with society, including healthcare services, shapes their attitudes toward their disabilities and toward healthcare. Nevertheless, this study contributes to preliminary relevant findings in understanding women with disabilities and outlines proposed health policy recommendations. This study also complements existing research into persons with disabilities as an under-represented population. Hopefully, the information resulting from this study could lead to further

research to provide evidence for women with disabilities, health services, and health policy makers in providing accommodative regulations and services.

5.7 Suggestions for further research

Throughout the interviews, there were questions regarding the comprehensiveness of disability management provided by the Indonesian government. I sought clarification regarding the marginalisation of women with disabilities in the healthcare system; the need for an improved healthcare system inclusive of the disabled community; and the influences of society on the disabled person. Even though the findings were limited to women with physical disability and impaired mobility, they are still valuable for further research for women with psychological, cognitive, and other types of disabilities along with their interactions with society.

From this study results, it is necessary to improve understanding of disability, gender, and its dimensions: women, disability, and the society construction. Further, the lack of collaboration between inter-agencies from the Indonesian government inaccurately represented the statistical profile of the disabled population. The improvement in methods of statistical data collection may untangle the confusing and overlapping data related to the disabled population. In regards to healthcare access, this study reveals the need for evaluation related to improved services and adequate treatment from healthcare provider. According to participants, the medical model only approach has no longer relevant to their condition. Thus, an alternative approach to provide a better accommodation for women with disabilities is needed.

From the preliminary findings, the study concludes with five priority areas to support the development and implementation of health policy for women with disabilities based on the understanding of the environment in Indonesia.

- 1) Extensive qualitative research toward women with disabilities in other provinces in Indonesia is a necessity. With the limitations of this study, arising from conversations with women with disability in one city only and from only one association, it will be worthwhile to commence similar studies in other cities/provinces and compare results in respect to gender differences, ethnicity and cultural sensitivity and differences in points of view. Through such undertakings, further consolidation of shared experiences and a more comprehensive understanding of women with disabilities would be gained.
- 2) Reflective of the Yogyakarta system, further knowledge of effective ways to strengthen local and regional systems are needed to empower disabled people's organisations/associations through consultation processes with government at the grass roots level. This will influence the policy-maker through evidence and education. A first step would be to unify and coordinate governing bodies and regulations. National standardization of terminology, measures, knowledge, and education, regarding disabilities, would enhance inter-ministerial cooperation, while simultaneously preserving the autonomy of the provinces. Such an approach is required to specify both the share of responsibility and allocation of functions.

- 3) Distinguishing the elderly from the disabled group as different populations could impact positively on the effectiveness of management of healthcare services for both the elderly and disabled groups.
- 4) Further research is needed to investigate and identify ways in which the government could provide more accommodating and more effective healthcare services for disabilities. In addition to that, the Indonesian government needs to establish a procedure to disseminate information and implement recommendations arising from specific study results as part of the improvement of attitudes toward disabilities in healthcare services.

5.8 Implications and recommendations for policy makers

The preliminary findings of this study are noteworthy. An important recommendation is to include the disabled community as stakeholders in the healthcare system in order to understand and bridge the gap between healthcare policy and its actual implementation. The case studies highlighted the importance of empowerment of the individual and/or community agents for promotion and education. Learning can be gleaned from the Yogyakarta government, which has been responsive and took action toward fulfilling the Convention on The Rights of Persons with Disabilities to the needs of disabled people.

The local government also created the atmosphere that allowed the community of disabled people to grow stronger and to engage. They did this through enabling the disabled community organisations to develop health education programs and to collaborate with Ministries of Health and Social Welfare. Even though this is a good sign,

it does not necessarily mean crucial improvements have happened. Within the period 2002 to 2012 only three local regulations were produced to complement central government regulations. Accommodative policies and actions are still needed and will depend on on-going collaboration. Findings from this study provide insight and evidence into what still needs to be done to promote change through grassroots community actions.

The Government needs to recognize the importance of the involvement of women with disabilities in research and in the utilisation of results arising from disability studies as it may contribute to decision-making. Local and regional organizations and communities do respond to create a supportive environment and to empower people with disabilities. This interaction requires a mutual investigation - the interaction of people with disabilities with the environment engaging the individuals in self-reporting and then relaying the results to the government. The recognition of contributions from parties such as people with disabilities, the researchers, and the government will provide valuable strategies and improve the engagement processes and will benefit the endeavour to implement improvements by simplifying the bureaucratic procedures; by developing research oriented programs focusing on women with disabilities that could be evolve into actions; by conducting continuous health research as a control or baseline of the actual health situation of women with disabilities; by undertaking regular inspections, supervision, monitoring, and evaluation of the program's implementation; and by instigating transparent reporting of the program's progress and achievements to the public. Larger endeavours ought to be divided into micro programs based on the

women's disability associations/organisations' specific membership or population to hasten the results.

The participants' interview results and the review of Indonesian government's policies on disabilities revealed the deficiency of the policy in regard to support of women with disabilities. Therefore, the following recommendations are imperative to this sector and should be considered in the process of developing health programs and policies for disabilities and for women with disabilities:

- 1) Re-analyse the health system, including access to services to identify the gaps in the provision of services in rural, remote, and disadvantaged areas. This could be initiated through national surveys for people with disabilities to explore healthcare access.
- 2) Create coherent and complementary policies to shore up the existing health policies and programs for people with disabilities in primary healthcare facilities. Provide disability-focused services, which include a women's health assessment.
- 3) Standard procedures in the treatment of women with disabilities need to be accompanied by training and education specific to disability for health personnel, assistive workers, and chaperones, in order to improve the service for patients with disabilities. These procedures in healthcare services should have a standardized and unified system of care to serve female patients with disabilities.
- 4) By providing disability assistance as part of service support, awareness of the needs of disabled persons in health services will increase and services will improve.

- 5) The separation of gerontology from the disability within healthcare will facilitate and accommodate the special needs of disabilities.
- 6) Partnerships between government representatives and disabilities organisations should be developed to create a master plan of the Indonesian government's Disability Boards, in order to contribute meaningful advice and perspectives in the health programs from ground level stakeholders. This involvement should not be limited to initial development and implementation stages, but should roll out to on-going advice, and follow-up of the programs.
- 7) Coordination between disability associations to organize health education, counselling, and promotion of health related issues regarding disability, including women's health, should occur, and also efforts should be focused on the provision of systems of supports for women with disabilities and their family and caregivers.
- 8) Educational and behavioural change programs for society can gain traction through religious organisations, neighbourhood community groups, youth organisations, and community family welfare programmes, drawing on community resources more comprehensively and effectively.
- 9) Add topics of health and physical education into classrooms, not limited to health issues, but to include some level of knowledge of disability that could impact children.

5.9 Conclusion

Current studies have identified that worldwide, governments have placed little attention on the health and welfare of women with disabilities. However, there are a

few studies that have investigated existing government policies around the world and their effectiveness for people with disabilities, yet none specific to women. As Indonesia has limited published studies in this field, this study has contributed to reducing this evidence gap in information by examining related literature and exploring how women with disabilities understand and manage their disabilities specifically when accessing healthcare services. Given the lack of information available on women with disabilities accessing healthcare services, this study proposed the following research questions to be answered. How do women with disabilities understand and describe their experiences of disability in their daily lives, and in accessing health services? What problems in access to health services can be identified based on the experiences of women with disabilities? And what factors can be isolated from this study of women with disabilities to formulate better policies that could improve access to the health services being investigated?

To answer the research questions this study selected a qualitative study design to investigate the experiences of nine women with physical disabilities, exploring their perceptions of disability, and it focused on identification and isolation of the problems in accessing healthcare services. The process was accomplished by conducting individual semi-structured interviews with the participants, the investigation included questions about their perceptions of disability, healthcare services received, interpersonal relationships, and social support. In answering the research questions, most women with disabilities in this study believed their disabilities could be affected by their perceptions of themselves.

In summary, there are three important aspects to be improved in order to create advancements on policy for disabled: improve the understanding of the concept of disability, enhance access and environmental support for disabled people, and guide changes to society's behaviour toward disabled people through education. It is evidenced that disability concepts in Indonesia are still related to the medical and charity model, where women with disabilities are required to be rehabilitated and assisted with financial aid. They are seen as a dependent, weak, and incompetent population even seen as incompetent to be pregnant, and to bear and raise children. Conversely, the majority of participants describe themselves oppositely to this depiction, through their achievement in academia and work, and as their way to counteract the stereotyping. They described themselves as smart, independent, and competent to be wives and mothers. In addition to this, gender characteristics influenced the participants' attention to their health conditions by seeking health assistance through their closest social support. Social support is known to be an important feature for individual encouragement. Closest families provide health literacy resulting in positive health help-seeking behaviours. This study reported that the disability peer group and school have not provided the support expected resulting in frustration and a sense of being unsupported. The participants who experienced unsupportive family, peers and schools tend to relate to the accepted stereotype.

Improvements in healthcare programs by the government affected the healthcare seeking behaviours of participants. Social health insurance improved patients' quality of life through pain rehabilitation and therapy. The services provided

under the same umbrella with the geriatric group must be separated due to them being two different sectors with different issues. Throughout this study, access to facilities and health worker's attitudes was a concern that required healthcare service provider strategies to accommodate actual needs. Disabled organizations and the involvement of women with disability, in consultation and policy writing, could complement the process of reducing the access challenges and would contribute to maximizing the well-being women with disabilities through strategic policies that reflect the rights of women with disabilities. Education and awareness through appropriate community links could inform the general public with accurate information to promote society's acceptance of disability.

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Appendices

Appendix A: Ethics Approval



HUMAN ETHICS COMMITTEE

Secretary, Lynda Griffioen
Email: human-ethics@canterbury.ac.nz

Ref: HEC 2015/92

26 August 2015

Dhita de LaRoche
School of Health Sciences
UNIVERSITY OF CANTERBURY

Dear Dhita

The Human Ethics Committee advises that your research proposal "Health policy recommendations for women with disabilities in Indonesia" has been considered and approved.

Please note that this approval is subject to the incorporation of the amendments you have provided in your email of 25 August 2015.

Best wishes for your project.

Yours sincerely

A handwritten signature in black ink, appearing to read 'L MacDonald'.

Lindsey MacDonald
Chair
University of Canterbury Human Ethics Committee

Appendix B: Authority Approval



**KEMENTERIAN DALAM NEGERI
REPUBLIK INDONESIA
DIREKTORAT JENDERAL POLITIK DAN PEMERINTAHAN UMUM**
JALAN MEDAN MERDEKA UTARA NO. 7 JAKARTA PUSAT 10110, Telp. 3454270

REKOMENDASI PENELITIAN

NOMOR440.02/436.1/Polpum....

- a. Dasar : 1. Peraturan Menteri Dalam Negeri Nomor 41 Tahun 2010 tentang Organisasi dan Tata Kerja Kementerian Dalam Negeri (Berita Negara Republik Indonesia Tahun 2010 Nomor 316), sebagaimana telah diubah dengan Peraturan Menteri Dalam Negeri Nomor 14 Tahun 2011 tentang Perubahan Atas Peraturan Menteri Dalam Negeri Nomor 41 Tahun 2010 tentang Organisasi dan Tata Kerja Kementerian Dalam Negeri (Berita Negara Republik Indonesia Tahun 2011 Nomor 168);
2. Peraturan Menteri Dalam Negeri Nomor 7 Tahun 2014 tentang Perubahan Atas Peraturan Menteri Dalam Negeri Nomor 64 Tahun 2011 tentang Pedoman Penerbitan Rekomendasi Penelitian;
- b. Menimbang : Surat Acting Head of School University of Canterbury Nomor 01 Tanggal 8 Oktober 2015 Perihal Permohonan Rekomendasi Penelitian.

MEMBERITAHUKAN BAHWA :

- a. Nama/ Obyek : Florentina Dhita Hardini.
- b. Jabatan/Tempat/ Identitas : Peneliti Utama / Jl. Gading Raya No 35 RT001/RW104 Kel. Pisangan Timur, Pulo Gadung, Jakarta Timur 13230 Telp. 08128369559 / No. KTP 3175025508770002.
- c. Untuk : 1) Melakukan penelitian, dengan proposal berjudul Health Policy Recommendations for Women with Disabilities in Indonesia (*Rekomendasi Kebijakan Kesehatan bagi Wanita Difabel di Indonesia*);
- 2) Lokasi penelitian : Provinsi D.I.Yogyakarta (1 provinsi);
- 3) Waktu/lama penelitian : Januari s.d. Juni 2016;
- 4) Anggota tim peneliti : -;
- 5) Bidang penelitian : Kesehatan;
- 6) Status penelitian : Baru.
- d. Melaporkan hasil penelitian kepada Menteri Dalam Negeri c.q. Dirjen Polpum, paling lambat 6 bulan setelah selesai penelitian.

Demikian rekomendasi ini dibuat untuk digunakan seperlunya.

Jakarta, 29 Desember 2015

a.n. DIREKTUR JENDERAL
POLITIK DAN PEMERINTAHAN UMUM
SEKRETARIS DITJEN,

BUDI PRASETYO, SH, MM
Pembina Utama Madya (IV/d)
NIP. 19570108 198703 1 001

Tembusan:

Yth. Gubernur Provinsi D.I.Yogyakarta;
up. Kaban Kesbang dan Linmas Prov.

Appendix C: Information sheet for disabilities association



Information Sheet

School of Health Sciences
Telephone: +64 22 425 6179
Email: fdh14@uclive.ac.nz
Date: ____/____/____

Health Policy Recommendations for Women with Disabilities in Indonesia

Information Sheet for Disabilities Association

My name is Dhita de LaRoche, Master of Health Science candidate from University of Canterbury. My involvement in this study is the solely researcher and interviewer for this study.

This research aims to understand the experiences from women with disabilities in their daily life and in accessing quality health services, recognize accessing health services problems and identify the factors involved in accessing health services to formulate a better policy to improve the access of health services.

For each participant there will be a reimbursement of IDR 100.000 (approximately NZ\$10 per interview per participant) as a thank-you payment to show appreciation of your time for undertaking the interview. At the end of the interview the payment will be handed directly to the participant/family/caregiver or a bank transfer will be undertaken to an account provided.

Your involvement in this project will be as the gatekeeper and advisor for the women with disabilities. An interview with participants will be an individual face-to-face or via phone interview for 1-2 hours or as long as she feels comfortable with, in a location of her choice. During the interview you may accompany the participant. A completed and signed consent form must be submitted in order for the interview to be held.

The interview will be recorded in an audiotape, which will assist in data collection, management, and analysis, and support accurate transcriptions from the interviews. Questions asked will be about her life with disability, what experiences she has/had, and the condition related with health access.

As a follow-up to this investigation, participant will not be asked to do anything further. Although, if further information is necessary; i.e. - analysis and data finding stage to clarify information participant provided, this will be performed typically via phone call by the researcher.

In the performance of the tasks and application of the procedures there are risks of emotional distress, which may be evoked when recalling upsetting experiences. If the researcher and representative are not successful in easing the risk, she/he will contact a third party for assistance, i.e. psychologist, counsellor, or hospital.

You may receive a copy of the project results by contacting the researcher at the conclusion of the project.

Participation is voluntary and she has the right to withdraw at any stage without penalty. If she withdraws, I will remove information relating to her until the point where their contribution is part of a larger body of work and/or submitted for publication of thesis exam.

The results of the project may be published, but she will be assured of the complete confidentiality of data gathered in this investigation: her identity will not be made public. To ensure anonymity and confidentiality, participants' identifying details from the informed consent will be coded for confidentiality. Identification such as names, address, and interview location will be replaced with a new code identification (pseudonym). This new identification will be used in transcription, note taking, audio, and analysis software. On paper, transcripts and notes that contain the original identification, identifying details will be erased with a permanent black marker. As for audio recording, editing for anonymisation is difficult; therefore, limited access to the audio information folder will be employed.

Both paper and audio files will be kept on a password secured folder on a secured computer, only accessed by the researcher.

Confidentiality, protection of information and the data gathered from this study will be done so as to not to publish the individual identity of any participants, rather the use of code words or pseudonyms will happen when writing up the interview notes. The recording will be backed up on USB/hard drive and these copies will be stored in a separate location from the original and will be kept for five years in lockable storage in the School of Health Sciences, at the University of Canterbury. Thereafter this material will be erased and destroyed. A thesis is a public document and will be available through the UC Library. The participant will receive a brief summary and results of the study.

The project is being carried out as a requirement for Master of Health Sciences by Dhita de LaRoche, under the supervision of Associate Professor Ray Kirk, who can be contacted at ray.kirk@canterbury.ac.nz and Dr Sarah Lovell at sarah.lovell@canterbury.ac.nz. They will be pleased to discuss any concerns you may have about participation in the project.

This project has been reviewed and approved by the University of Canterbury Human Ethics Committee, and participants should address any complaints to The Chair, Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).

If you agree to participate in the study, you are asked to complete the consent form and return it using the provided pre-paid postage addressed envelope to the address below before ____/____/____

- To: Dhita de LaRoche
SAPDA Yogya
- Address: Komplek BNI No. 25 Patangpuluhan
Wirobrajan, Yogyakarta, Indonesia 55252
- Phone: +62 274 384 066
- Fax: +62 274 384 066
- Email: info@sapdajogja.org

Researcher,
Dhita de LaRoche

Lembar Informasi

School of Health Sciences
Telepon: +64 22 425 6179
Email: fdh14@uclive.ac.nz

Date: ____/____/____

Rekomendasi Kebijakan Kesehatan bagi Wanita Difabel di Indonesia

Lembar Informasi untuk Asosiasi Difabel

Nama saya Dhita de LaRoche, kandidat Paska Sarjana Ilmu Kesehatan dari Universitas Canterbury. Keterlibatan saya dalam penelitian ini hanya sebagai peneliti dan pewawancara untuk study ini.

Penelitian ini bertujuan untuk memahami pengalaman wanita difabel dalam kehidupan sehari-hari dan dalam mengakses layanan kesehatan yang berkualitas, mengidentifikasi masalah dan factor-faktor dalam mengakses pelayanan kesehatan kemudian nantinya digunakan untuk merumuskan kebijakan yang lebih baik untuk meningkatkan kualitas layanan kesehatan.

Untuk setiap peserta akan ada uang penggantian sebesar Rp 100.000 sebagai ucapan terima kasih sebagai penghargaan untuk waktunya melakukan wawancara. Pada akhir wawancara pembayaran akan diserahkan langsung kepada peserta / keluarga / pengasuh atau transfer ke rekening yang disediakan.

Keterlibatan Anda dalam studi ini sebagai penjaga gerbang dan penasehat bagi wanita difabel. Wawancara dengan peserta dapat dilakukan melalui telepon atau tatap muka selama 1-2 jam atau waktu yang diinginkan peserta di lokasi pilihannya. Selama wawancara Anda diperbolehkan menemani peserta. Formulir persetujuan wajib diisi dan ditandatangani dan diserahkan sebelum atau pada saat wawancara.

Wawancara akan disimpan dalam bentuk rekaman suara, yang akan membantu dalam pengumpulan data, manajemen, dan analisis, dan mendukung keakuratan transkripsi dari wawancara.

Pertanyaan yang diajukan mengenai kehidupannya berkaitan dengan disabilitas, pengalamannya, dan kondisinya terkait dengan akses kesehatan.

Sebagai tindak lanjut penelitian ini, peserta tidak akan diminta untuk melakukan apa-apa lagi. Namun jika informasi lebih lanjut diperlukan; misalnya – dalam tahap analisis dan temuan data membutuhkan informasi yang lebih jelas dari peserta, tindak lanjut ini akan dilakukan melalui telepon oleh peneliti.

Pada saat pelaksanaan penelitian dan penerapan prosedur dapat muncul risiko gangguan emosi, yang dapat bangkit karena mengingat pengalaman yang tidak mengenakan. Jika pihak peneliti dan perwakilan tidak berhasil menurunkan risiko, mereka akan menghubungi pihak ketiga untuk bantuan, misalnya: psikolog, konselor, atau rumah sakit.

Anda dapat menerima salinan hasil proyek dengan menghubungi peneliti pada akhir proyek.

Partisipasi bersifat sukarela dan dapat mengundurkan diri setiap saat tanpa sangsi. Penarikan diri dari partisipasi termasuk dalam hal informasi yang telah diberikan sampai di mana bagian informasi yang diberikan sudah menjadi bagian besar dari pembuatan tesis atau untuk publikasi ujian tesis.

Hasil dari penelitian ini dapat dipublikasikan, tapi kerahasiaan dari identitas lengkap yang dikumpulkan dalam penelitian ini tidak akan dipublikasikan. Untuk memastikan anonimitas dan kerahasiaan, rincian identitas peserta formulir persetujuan akan diubah menjadi kode rahasia. Identifikasi seperti nama, alamat, dan lokasi wawancara akan diganti dengan identifikasi kode baru (nama samaran). Identifikasi baru ini akan digunakan dalam transkripsi, pencatatan, rekaman suara, dan analisis perangkat lunak. Di kertas formulir, transkrip dan catatan yang berisi identifikasi asli, rincian identifikasi akan dihapus dengan spidol hitam permanen. Sedangkan untuk rekaman audio, mengeditnya menjadi anonim sulit dilakukan; oleh karena itu akses ke data akan menjadi sangat terbatas.

Data berupa kertas dan rekaman suara akan disimpan pada folder dengan sandi dalam komputer yang aman dan hanya diakses oleh peneliti.

Kerahasiaan, perlindungan informasi dan data yang dikumpulkan dari penelitian ini akan dikelola sedemikian hingga tidak mempublikasikan identitas individu dari setiap peserta, menggunakan kode atau nama samaran ketika menulis catatan wawancara. Rekaman akan disimpan di USB / hard drive dan salinannya akan disimpan di lokasi yang terpisah dari aslinya dan akan terus disimpan di lemari terkunci di Sekolah Ilmu Kesehatan, Universitas Canterbury selama lima tahun. Setelah itu data ini akan dihapus dan dihancurkan. Tesis adalah dokumen publik dan akan tersedia melalui Perpustakaan UC. Peserta akan menerima ringkasan singkat dan hasil penelitian.

Proyek ini dilakukan sebagai syarat untuk mendapatkan gelar Paska Sarjana Ilmu Kesehatan oleh Dhita de LaRoche, di bawah pengawasan Associate Professor Ray Kirk, yang dapat dihubungi melalui email: ray.kirk@canterbury.ac.nz dan Dr Sarah Lovell di email: sarah.lovell@canterbury.ac.nz. Mereka akan dengan senang hati membicarakan masalah yang muncul dalam partisipasi penelitian ini.

Penelitian ini telah ditinjau dan disetujui oleh Komite Etik University Canterbury dan dapat mengajukan komplemen ke Ketua Komite Etik, University of Canterbury, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).

Jika anda menyetujui untuk berpartisipasi dalam studi ini, anda diminta untuk mengirimkan formulir persetujuan yang sudah ditandatangani dan mengembalikannya menggunakan amplop berperangko yang telah disediakan ke alamat di bawah ini sebelum ____/____/____

- Kepada: Dhita de LaRoche
SAPDA Yogya
- Alamat: Komplek BNI No. 25 Patangpuluhan
Wirobrajan, Yogyakarta, Indonesia 55252
- Telepon: +62 274 384 066
- Fax: +62 274 384 066
- Email: info@sapdajogja.org

Peneliti,
Dhita de LaRoche

Appendix D: Information sheet for family/caregiver



Information Sheet

School of Health Sciences
Telephone: +64 22 425 6179
Email: fdh14@uclive.ac.nz
Date: ____/____/____

Health Policy Recommendations for Women with Disabilities in Indonesia

Information Sheet for Family/Caregiver

My name is Dhita de LaRoche, Master of Health Science candidate from the University of Canterbury. My involvement in this study is as solely a researcher and interviewer for this study.

This research aims to understand the experiences from women with disabilities in their daily life and in accessing quality health services, recognise accessing health services problems and identify the factors involved in accessing health services to formulate a better policy to improve the access of health services.

For each participant there will be a reimbursement of IDR 100.000 (approximately NZ\$10 per interview per participant) as a thank-you payment to show appreciation of your time for undertaking the interview. At the end of the interview the payment will be handed directly to the participant/family/caregiver or a bank transfer will be undertaken to an account provided.

Your involvement in this project will be by acting on behalf of participant to participate in an individual face-to-face or via phone interview for 1-2 hours or as long as she feels comfortable with, in a location of her choice. During the interview you may accompany the participant. A completed and signed consent form must be submitted in order for the interview to be held.

The interview will be recorded using an audiotape, which will assist in data collection, management, and analysis, and support accurate transcriptions from the interviews. There will be opportunities for you to listen to the recording at the end of the interview and to read the transcription when it is transcribed into note form and make any corrections, add any further information or delete information from the transcription. Questions asked will be about her life with disability, what experiences she has/had, and the condition related with health access.

As a follow-up to this investigation, you will not be asked to do anything further. Although, if further information is necessary; i.e. - analysis and data finding stage to clarify information you provided, this will be performed typically via phone call by the researcher.

In the performance of the tasks and application of the procedures there are risks of emotional distress, which may be evoked when recalling upsetting experiences. If the researcher and representative are not successful in easing the risk, she/he will contact a third party for assistance, i.e. psychologist, counsellor, or hospital.

You may receive a copy of the project results by contacting the researcher at the conclusion of the project.

Participation is voluntary and she has the right to withdraw at any stage without penalty. If she withdraws, I will remove information relating to her until the point where their contribution is part of a larger body of work and/or submitted for publication of thesis exam.

The results of the project may be published, but she will be assured of the complete confidentiality of data gathered in this investigation: her identity will not be made public. To ensure anonymity and confidentiality, participants' identifying details from the informed consent will be coded for confidentiality. Identification such as names, address, and interview location will be replaced with a new code identification (pseudonym). This new identification will be used in transcription, note taking, audio, and analysis software. On paper, transcripts and notes that contain the original identification, identifying details will be erased with a permanent black marker. As for audio recording, editing for anonymisation is difficult; therefore, limited access to the audio information folder will be employed.

Both paper and audio files will be kept on a password secured folder on a secured computer, only accessed by the researcher.

Confidentiality, protection of information and the data gathered from this study will be done so as to not to publish the individual identity of any participants, rather the use of code words or pseudonyms will happen when writing up the interview notes.

The recording will be backed up on USB/hard drive and these copies will be stored in a separate location from the original and will be kept for five years in lockable storage in the School of Health Sciences, at the University of Canterbury. Thereafter this material will be erased and destroyed. A thesis is a public document and will be available through the UC Library. The participant will receive a brief summary and results of the study.

The project is being carried out as a requirement for the Master of Health Sciences by Dhita de LaRoche, under the supervision of Associate Professor Ray Kirk, who can be contacted at ray.kirk@canterbury.ac.nz and Dr Sarah Lovell at sarah.lovell@canterbury.ac.nz. They will be pleased to discuss any concerns you may have about participation in the project.

This project has been reviewed and approved by the University of Canterbury Human Ethics Committee, and participants should address any complaints to The Chair, Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).

If you agree to participate in the study, you are asked to complete the consent form and return it using the provided pre-paid postage addressed envelope to the address below before ____/____/____

- To: Dhita de LaRoche
SAPDA Yogya
- Address: Komplek BNI No. 25 Patangpuluhan
Wirobrajan, Yogyakarta, Indonesia 55252
- Phone: +62 274 384 066
- Fax: +62 274 384 066
- Email: info@sapdajogja.org

Researcher,
Dhita de LaRoche

Lembar Informasi

School of Health Sciences
Telepon: +64 22 425 6179
Email: fdh14@uclive.ac.nz

Date: ____/____/____

Rekomendasi Kebijakan Kesehatan bagi Wanita Difabel di Indonesia

Lembar Informasi untuk Keluarga/Pengasuh

Nama saya Dhita de LaRoche, kandidat Paska Sarjana Ilmu Kesehatan dari Universitas Canterbury. Keterlibatan saya dalam penelitian ini hanya sebagai peneliti dan pewawancara untuk study ini.

Penelitian ini bertujuan untuk memahami pengalaman wanita difabel dalam kehidupan sehari-hari dan dalam mengakses layanan kesehatan yang berkualitas, mengidentifikasi masalah dan factor-faktor dalam mengakses pelayanan kesehatan kemudian nantinya digunakan untuk merumuskan kebijakan yang lebih baik untuk meningkatkan kualitas layanan kesehatan.

Untuk setiap peserta akan ada uang penggantian sebesar Rp 100.000 sebagai ucapan terima kasih sebagai penghargaan untuk waktunya melakukan wawancara. Pada akhir wawancara pembayaran akan diserahkan langsung kepada peserta / keluarga / pengasuh atau transfer ke rekening yang disediakan.

Keterlibatan Anda dalam studi ini sebagai wakil wanita difabel dalam wawancara melalui telepon atau tatap muka selama 1-2 jam atau waktu yang diinginkan peserta di lokasi pilihannya. Selama wawancara Anda diperbolehkan menemani peserta. Formulir persetujuan wajib diisi dan ditandatangani dan diserahkan sebelum atau pada saat wawancara.

Wawancara akan disimpan dalam bentuk rekaman suara, yang akan membantu dalam pengumpulan data, manajemen, dan analisis, dan mendukung keakuratan transkripsi dari wawancara. Akan ada kesempatan bagi anda untuk mendengarkan rekaman di

akhir wawancara and membaca transkripsi ketika diubah dari suara menjadi tulisan, dan dipersilakan untuk membuat koreksi, menambah atau mengurangi informasi dari transkripsi tersebut.

Pertanyaan yang diajukan mengenai kehidupannya berkaitan dengan disabilitas, pengalamannya, dan kondisinya terkait dengan akses kesehatan.

Sebagai tindak lanjut penelitian ini, peserta tidak akan diminta untuk melakukan apa-apa lagi. Namun jika informasi lebih lanjut diperlukan; misalnya – dalam tahap analisis dan temuan data membutuhkan informasi yang lebih jelas dari peserta, tindak lanjut ini akan dilakukan melalui telepon oleh peneliti.

Pada saat pelaksanaan penelitian dan penerapan prosedur dapat muncul risiko gangguan emosi, yang dapat bangkit karena mengingat pengalaman yang tidak mengenakan. Jika pihak peneliti dan perwakilan tidak berhasil menurunkan risiko, mereka akan menghubungi pihak ketiga untuk bantuan, misalnya: psikolog, konselor, atau rumah sakit.

Anda dapat menerima salinan hasil proyek dengan menghubungi peneliti pada akhir proyek.

Partisipasi bersifat sukarela dan dapat mengundurkan diri setiap saat tanpa sangsi. Penarikan diri dari partisipasi termasuk dalam hal informasi yang telah diberikan sampai di mana bagian informasi yang diberikan sudah menjadi bagian besar dari pembuatan tesis atau untuk publikasi ujian tesis.

Hasil dari penelitian ini dapat dipublikasikan, tapi kerahasiaan dari identitas lengkap yang dikumpulkan dalam penelitian ini tidak akan dipublikasikan. Untuk memastikan anonimitas dan kerahasiaan, rincian identitas peserta formulir persetujuan akan diubah menjadi kode rahasia. Identifikasi seperti nama, alamat, dan lokasi wawancara akan diganti dengan identifikasi kode baru (nama samaran). Identifikasi baru ini akan digunakan dalam transkripsi, pencatatan, rekaman suara, dan analisis perangkat lunak. Di kertas formulir, transkrip dan catatan yang berisi identifikasi asli, rincian identifikasi akan dihapus dengan spidol hitam permanen. Sedangkan untuk rekaman audio, mengeditnya menjadi anonim sulit dilakukan; oleh karena itu akses ke data akan menjadi sangat terbatas.

Data berupa kertas dan rekaman suara akan disimpan pada folder dengan sandi dalam komputer yang aman dan hanya diakses oleh peneliti.

Kerahasiaan, perlindungan informasi dan data yang dikumpulkan dari penelitian ini akan dikelola sedemikian hingga tidak mempublikasikan identitas individu dari setiap peserta, menggunakan kode atau nama samaran ketika menulis catatan wawancara. Rekaman akan disimpan di USB / hard drive dan salinannya akan disimpan di lokasi yang terpisah dari aslinya dan akan terus disimpan di lemari terkunci di Sekolah Ilmu Kesehatan, Universitas Canterbury selama lima tahun. Setelah itu data ini akan dihapus dan dihancurkan. Tesis adalah dokumen publik dan akan tersedia melalui Perpustakaan UC. Peserta akan menerima ringkasan singkat dan hasil penelitian.

Proyek ini dilakukan sebagai syarat untuk mendapatkan gelar Paska Sarjana Ilmu Kesehatan oleh Dhita de LaRoche, di bawah pengawasan Associate Professor Ray Kirk, yang dapat dihubungi melalui email: ray.kirk@canterbury.ac.nz dan Dr Sarah Lovell di email: sarah.lovell@canterbury.ac.nz. Mereka akan dengan senang hati membicarakan masalah yang muncul dalam partisipasi penelitian ini.

Penelitian ini telah ditinjau dan disetujui oleh Komite Etik University Canterbury dan dapat mengajukan komplemen ke Ketua Komite Etik, University of Canterbury, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).

Jika anda menyetujui untuk berpartisipasi dalam studi ini, anda diminta untuk mengirimkan formulir persetujuan yang sudah ditandatangani dan mengembalikannya menggunakan amplop berperangko yang telah disediakan ke alamat di bawah ini sebelum ____/____/____

- Kepada: Dhita de LaRoche
SAPDA Yogya
- Alamat: Komplek BNI No. 25 Patangpuluhan
Wirobrajan, Yogyakarta, Indonesia 55252
- Telepon: +62 274 384 066
- Fax: +62 274 384 066
- Email: info@sapdajogja.org

Peneliti,
Dhita de LaRoche

Appendix E: Information sheet for participants



Information Sheet

School of Health Sciences
Telephone: +64 22 425 6179
Email: fdh14@uclive.ac.nz

Date: ____/____/____

Health Policy Recommendations for Women with Disabilities in Indonesia

Information Sheet for Participants

My name is Dhita de LaRoche, Master of Health Science candidate from University of Canterbury. My involvement in this study is the solely researcher and interviewer for this study.

This research aims is to understand the experiences from women with disabilities in their daily life and in accessing quality health services, recognise the accessing health services problems and identify the factors to formulate a better policy to improve the access of health services.

For each participant there will be a reimbursement of IDR 100.000 (approximately NZ\$10 per interview per participant) as a thank-you payment to show appreciation of your time for undertaking the interview. At the end of the interview the payment will be handed directly to the participant/family/caregiver or a bank transfer will be undertaken to an account provided.

Your involvement in this project will be to participate in an individual face-to-face or via phone interview for 1-2 hours or as long as you feel comfortable with, in a location of your choice. During the interview you may be accompanied by a family member or a caregiver. A completed and signed consent form must be submitted in order the interview to be held.

The interview will be recorded in an audiotape, which will assist in data collection, management, and analysis, and support accurate transcriptions from the interviews.

There will be opportunities for participants to listen to the recording at the end of the interview and to read the transcription when it is transcribed into note form and make any corrections, add any further information or delete information from the transcription.

Questions asked will be about your life with disability, what experiences you have/had, and the condition related with health access.

As a follow-up to this investigation, you will not be asked to do anything further. Although, if further information is necessary; i.e. - analysis and data finding stage to clarify information you provided, this will be performed typically via phone call by the researcher.

In the performance of the tasks and application of the procedures there are risks of emotional distress, which may be evoked when recalling upsetting experiences. If the researcher and representative are not successful in easing the risk, she/he will contact a third party for assistance, i.e. psychologist, counsellor, or hospital.

You may receive a copy of the project results by contacting the researcher at the conclusion of the project.

Participation is voluntary and you have the right to withdraw at any stage without penalty. If you withdraw, I will remove information relating to you until the point where their contribution is part of a larger body of work and/or submitted for publication of thesis exam.

The results of the project may be published, but you will be assured of the complete confidentiality of data gathered in this investigation: your identity will not be made public. To ensure anonymity and confidentiality, participants' identifying details from the informed consent will be coded for confidentiality. Identification such as names, address, and interview location will be replaced with a new code identification (pseudonym). This new identification will be used in transcription, note taking, audio, and analysis software. On paper, transcripts and notes that contain the original identification, identifying details will be erased with a permanent black marker. As for audio recording, editing for anonymisation is difficult; therefore, limited access to the audio information folder will be employed.

Both paper and audio files will be kept on a password secured folder on a secured computer, only accessed by the researcher.

Confidentiality, protection of information and the data gathered from this study will be done so as to not to publish the individual identity of any participants, rather the use of code words or pseudonyms will happen when writing up the interview notes.

The recording will be backed up on USB/hard drive and these copies will be stored in a separate location from the original and will be kept for five years in lockable storage in the School of Health Sciences, at the University of Canterbury. Thereafter this material will be erased and destroyed. A thesis is a public document and will be available through the UC Library. The participant will receive a brief summary and results of the study.

The project is being carried out as a requirement for Master of Health Sciences by Dhita de LaRoche, under the supervision of Associate Professor Ray Kirk, who can be contacted at ray.kirk@canterbury.ac.nz and Dr Sarah Lovell at sarah.lovell@canterbury.ac.nz. They will be pleased to discuss any concerns you may have about participation in the project.

This project has been reviewed and approved by the University of Canterbury Human Ethics Committee, and participants should address any complaints to The Chair, Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).

If you agree to participate in the study, you are asked to complete the consent form and return it using the provided pre-paid postage addressed envelope to the address below before ____/____/____

- To: Dhita de LaRoche
SAPDA Yogya
- Address: Komplek BNI No. 25 Patangpuluhan
Wirobrajan, Yogyakarta, Indonesia 55252
- Phone: +62 274 384 066
- Fax: +62 274 384 066
- Email: info@sapdajogja.org

Researcher,
Dhita de LaRoche

Lembar Informasi

School of Health Sciences
Telepon: +64 22 4256179
Email: fdh14@uclive.ac.nz

Date: ____/____/____

Rekomendasi Kebijakan Kesehatan bagi Wanita Difabel di Indonesia

Lembar Informasi untuk Peserta

Nama saya Dhita de LaRoche, kandidat Paska Sarjana Ilmu Kesehatan dari Universitas Canterbury. Keterlibatan saya dalam penelitian ini hanya sebagai peneliti dan pewawancara untuk study ini.

Penelitian ini bertujuan untuk memahami pengalaman wanita difabel dalam kehidupan sehari-hari dan dalam mengakses layanan kesehatan yang berkualitas, mengidentifikasi masalah dan factor-faktor dalam mengakses pelayanan kesehatan kemudian nantinya digunakan untuk merumuskan kebijakan yang lebih baik untuk meningkatkan kualitas layanan kesehatan.

Untuk setiap peserta akan ada uang penggantian sebesar Rp 100.000 sebagai ucapan terima kasih sebagai penghargaan untuk waktunya melakukan wawancara. Pada akhir wawancara pembayaran akan diserahkan langsung kepada peserta / keluarga / pengasuh atau transfer ke rekening yang disediakan.

Keterlibatan Anda dalam studi ini sebagai peserta yang mewakili wanita difabel dengan wawancara melalui telepon atau tatap muka selama 1-2 jam atau waktu yang diinginkan dan di lokasi yang menjadi pilihan anda. Selama wawancara Anda diperbolehkan ditemani oleh keluarga/pengasuh. Formulir persetujuan wajib diisi dan ditandatangani dan diserahkan sebelum atau pada saat wawancara.

Wawancara akan disimpan dalam bentuk rekaman suara, yang akan membantu dalam pengumpulan data, manajemen, dan analisis, dan mendukung keakuratan transkripsi dari wawancara. Akan ada kesempatan bagi anda untuk mendengarkan rekaman di

akhir wawancara and membaca transkripsi ketika diubah dari suara menjadi tulisan, dan dipersilakan untuk membuat koreksi, menambah atau mengurangi informasi dari transkripsi tersebut.

Pertanyaan yang diajukan mengenai kehidupan anda berkaitan dengan disabilitas, pengalaman, dan kondisi terkait dengan akses kesehatan.

Sebagai tindak lanjut penelitian ini, peserta tidak akan diminta untuk melakukan apa-apa lagi. Namun jika informasi lebih lanjut diperlukan; misalnya – dalam tahap analisis dan temuan data membutuhkan informasi yang lebih jelas dari peserta, tindak lanjut ini akan dilakukan melalui telepon oleh peneliti.

Pada saat pelaksanaan penelitian dan penerapan prosedur dapat muncul risiko gangguan emosi, yang dapat bangkit karena mengingat pengalaman yang tidak mengenakan. Jika pihak peneliti dan perwakilan tidak berhasil menurunkan risiko, mereka akan menghubungi pihak ketiga untuk bantuan, misalnya: psikolog, konselor, atau rumah sakit.

Anda dapat menerima salinan hasil proyek dengan menghubungi peneliti pada akhir proyek.

Partisipasi bersifat sukarela dan dapat mengundurkan diri setiap saat tanpa sangsi. Penarikan diri dari partisipasi termasuk dalam hal informasi yang telah diberikan sampai di mana bagian informasi yang diberikan sudah menjadi bagian besar dari pembuatan tesis atau untuk publikasi ujian tesis.

Hasil dari penelitian ini dapat dipublikasikan, tapi kerahasiaan dari identitas lengkap yang dikumpulkan dalam penelitian ini tidak akan dipublikasikan. Untuk memastikan anonimitas dan kerahasiaan, rincian identitas peserta formulir persetujuan akan diubah menjadi kode rahasia. Identifikasi seperti nama, alamat, dan lokasi wawancara akan diganti dengan identifikasi kode baru (nama samaran). Identifikasi baru ini akan digunakan dalam transkripsi, pencatatan, rekaman suara, dan analisis perangkat lunak. Di kertas formulir, transkrip dan catatan yang berisi identifikasi asli, rincian identifikasi akan dihapus dengan spidol hitam permanen. Sedangkan untuk rekaman audio, mengeditnya menjadi anonim sulit dilakukan; oleh karena itu akses ke data akan menjadi sangat terbatas.

Data berupa kertas dan rekaman suara akan disimpan pada folder dengan sandi dalam komputer yang aman dan hanya diakses oleh peneliti.

Kerahasiaan, perlindungan informasi dan data yang dikumpulkan dari penelitian ini akan dikelola sedemikian hingga tidak mempublikasikan identitas individu dari setiap peserta, menggunakan kode atau nama samaran ketika menulis catatan wawancara. Rekaman akan disimpan di USB / hard drive dan salinannya akan disimpan di lokasi yang terpisah dari aslinya dan akan terus disimpan di lemari terkunci di Sekolah Ilmu Kesehatan, Universitas Canterbury selama lima tahun. Setelah itu data ini akan dihapus dan dihancurkan. Tesis adalah dokumen publik dan akan tersedia melalui Perpustakaan UC. Peserta akan menerima ringkasan singkat dan hasil penelitian.

Proyek ini dilakukan sebagai syarat untuk mendapatkan gelar Paska Sarjana Ilmu Kesehatan oleh Dhita de LaRoche, di bawah pengawasan Associate Professor Ray Kirk, yang dapat dihubungi melalui email: ray.kirk@canterbury.ac.nz dan Dr Sarah Lovell di email: sarah.lovell@canterbury.ac.nz. Mereka akan dengan senang hati membicarakan masalah yang muncul dalam partisipasi penelitian ini.

Penelitian ini telah ditinjau dan disetujui oleh Komite Etik University Canterbury dan dapat mengajukan komplemen ke Ketua Komite Etik, University of Canterbury, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).

Jika anda menyetujui untuk berpartisipasi dalam studi ini, anda diminta untuk mengirimkan formulir persetujuan yang sudah ditandatangani dan mengembalikannya menggunakan amplop berperangko yang telah disediakan ke alamat di bawah ini sebelum ____/____/____

- Kepada: Dhita de LaRoche
SAPDA Yogya
- Alamat: Komplek BNI No. 25 Patangpuluhan
Wirobrajan, Yogyakarta, Indonesia 55252
- Telepon: +62 274 384 066
- Fax: +62 274 384 066
- Email: info@sapdajogja.org

Peneliti,
Dhita de LaRoche

Appendix F: Consent form for disabilities association



Consent Form

School of Health Sciences
Telephone: +64 22 425 6179
Email: fdh14@uclive.ac.nz

Health Policy Recommendations for Women with Disabilities in Indonesia

Consent Form for Disabilities Association

I have been given a full explanation of this project and have had the opportunity to ask questions.

I understand what is required of the participant if she agrees to take part in the research.

I understand that there will be an interview held in a location of her choice.

I understand that her family/caregiver is allowed to accompany her during the interview.

I understand that participation is voluntary and the participant may withdraw at any time without penalty. Withdrawal of participation will also include the withdrawal of any information she has provided until the point where the contribution is part of a larger body of work and/or submitted for publication of thesis exam.

I understand that any information or opinions the participant provides will be kept confidential to the researcher and supervisor, and that any published or reported results will not identify the participants and disability association. I understand that a thesis is a public document and will be available through the UC Library.

I understand that all data collected (notes taking, transcripts, audio files) for the study will be kept in locked and secure facilities and/or in password protected electronic form and will be destroyed after five years.

I understand the risks associated with taking part and how they will be managed.

I understand that the participant and I are able to receive a report on the findings of the study by contacting the researcher at the conclusion of the project.

I understand that I can contact the researcher, Dhita de LaRoche, phone: +64 22 4256179, email: fdh14@uclive.ac.nz or supervisor, Associate Professor Ray Kirk, phone: +64 3 364 3108, email: ray.kirk@canterbury.ac.nz and Dr Sarah Lovell, email: sarah.lovell@canterbury.ac.nz for further information. If I have any complaints, I can contact the Chair of the University of Canterbury Human Ethics Committee, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).

By signing below, I agree to participate in this research project.

Association name: _____

Date: _____

Signature: _____

Please return this consent form using the provided pre-paid postage addressed envelope to the address below before ____/____/____

- To: Dhita de LaRoche
SAPDA Yogya
- Address: Komplek BNI No. 25 Patangpuluhan
Wirobrajan, Yogyakarta, Indonesia 55252
- Phone: +62 274 384 066
- Fax: +62 274 384 066
- Email: info@sapdajogja.org

Researcher,
Dhita de LaRoche

Formulir Persetujuan

School of Health Sciences
Telepon: +64 22 425 6179
Email: fdh14@uclive.ac.nz

Rekomendasi Kebijakan Kesehatan bagi Wanita Difabel di Indonesia

Formulir Persetujuan untuk Asosiasi Difabel

Saya telah diberi penjelasan lengkap mengenai penelitian ini dan diberikan kesempatan untuk mengajukan pertanyaan.

Saya mengerti apa yang dibutuhkan dari peserta jika dia menyetujui untuk turut serta dalam penelitian ini.

Saya mengerti bahwa akan dilakukan wawancara yang lokasinya ditentukan oleh peserta.

Saya mengerti bahwa keluarganya / pengasuh diperbolehkan untuk menemani peserta selama wawancara berlangsung.

Saya mengerti bahwa partisipasi bersifat sukarela dan peserta dapat mengundurkan diri setiap saat tanpa sangsi. Penarikan diri dari partisipasi termasuk dalam hal informasi yang telah diberikan sampai di mana bagian informasi yang diberikan sudah menjadi bagian besar dari pembuatan tesis atau untuk publikasi ujian tesis.

Saya memahami bahwa setiap informasi atau opini dari peserta akan dirahasiakan oleh peneliti dan pengawas, dan bila ada hasil yang dipublikasikan atau dilaporkan tidak akan mengidentifikasi peserta dan asosiasi difabel. Saya mengerti bahwa tesis adalah dokumen publik dan akan tersedia melalui Perpustakaan UC.

Saya memahami bahwa semua data yang dikumpulkan (catatan, transkrip, rekaman) untuk penelitian akan disimpan dalam fasilitas yang aman dan dilindungi oleh kunci dan/

atau disimpan dalam bentuk elektronik dan dilindungi oleh sandi dan akan dihancurkan setelah lima tahun.

Saya memahami risiko terkait dengan mengambil bagian dalam penelitian ini dan bagaimana resiko tersebut akan dikelola.

Saya mengerti bahwa saya dan peserta dapat menerima laporan mengenai penelitian ini dengan menghubungi peneliti di akhir studi.

Saya memahami bahwa saya bisa menghubungi peneliti, Dhita de LaRoche, phone: +64 22 4256179, email: fdh14@uclive.ac.nz or supervisor, Associate Professor Ray Kirk, phone: +64 3 364 3108, email: ray.kirk@canterbury.ac.nz and Dr Sarah Lovell, email: sarah.lovell@canterbury.ac.nz untuk info lebih lanjut. Jika saya memiliki keluhan, saya dapat menghubungi Ketua Komite Etik, University of Canterbury, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).

Dengan menandatangani, saya setuju untuk berpartisipasi dalam proyek penelitian ini.

Nama Asosiasi: _____

Tanggal: _____

Tanda tangan: _____

Mohon kembalikan formulir persetujuan ini menggunakan amplop berperangko yang telah disediakan ke alamat di bawah ini sebelum ____/____/____

- Kepada: Dhita de LaRoche
SAPDA Yogya
- Alamat: Komplek BNI No. 25 Patangpuluhan
Wirobrajan, Yogyakarta, Indonesia 55252
- Telepon: +62 274 384 066
- Fax: +62 274 384 066
- Email: info@sapdajogja.org

Peneliti,
Dhita de LaRoche

Appendix G: Consent form for family/caregiver



Consent Form

School of Health Sciences
Telephone: +64 22 425 6179
Email: fdh14@uclive.ac.nz

Health Policy Recommendations for Women with Disabilities in Indonesia

Consent Form for Family/Caregiver

I have been given a full explanation of this project and have had the opportunity to ask questions.

I understand what is required of the participant if she agrees to take part in the research.

I understand that I need to be present for the interview.

I understand that participation is voluntary and the participant may withdraw at any time without penalty. Withdrawal of participation will also include the withdrawal of any information she has provided until the point where the contribution is part of a larger body of work and/or submitted for publication of thesis exam.

I understand that any information or opinions the participant provides will be kept confidential to the researcher and supervisor, and that any published or reported results will not identify the participants or the disability association. I understand that a thesis is a public document and will be available through the UC Library.

I understand that all data collected (notes taking, transcripts, audio files) for the study will be kept in locked and secure facilities and/or in password protected electronic form and will be destroyed after five years.

I understand the risks associated with taking part and how they will be managed.

I understand that I am able to receive a report on the findings of the study by contacting the researcher at the conclusion of the project.

I confirm that the participant is a woman aged 18 years and above, experiencing disability, lives in Indonesia and is a member of SAPDA (Sentra Advokasi Perempuan, Difabel dan Anak).

I understand that I can contact the researcher, Dhita de LaRoche, phone: +64 22 4256179, email: fdh14@uclive.ac.nz or supervisor, Associate Professor Ray Kirk, phone: +64 3 364 3108, email: ray.kirk@canterbury.ac.nz and Dr Sarah Lovell, email: sarah.lovell@canterbury.ac.nz for further information. If I have any complaints, I can contact the Chair of the University of Canterbury Human Ethics Committee, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).

By signing below, I agree to participate in this research project.

Name: _____

Date: _____

Signature: _____

Please return this consent form using the provided pre-paid postage addressed envelope to the address below before ____/____/____

- To: Dhita de LaRoche
SAPDA Yogya
- Address: Komplek BNI No. 25 Patangpuluhan
Wirobrajan, Yogyakarta, Indonesia 55252
- Phone: +62 274 384 066
- Fax: +62 274 384 066
- Email: info@sapdajogja.org

Researcher,
Dhita de LaRoche

Formulir Persetujuan

School of Health Sciences
Telepon: +64 22 4256179
Email: fdh14@uclive.ac.nz

Rekomendasi Kebijakan Kesehatan bagi Wanita Difabel di Indonesia

Formulir Persetujuan untuk Keluarga/Pengasuh

Saya telah diberi penjelasan lengkap mengenai penelitian ini dan diberikan kesempatan untuk mengajukan pertanyaan.

Saya mengerti apa yang dibutuhkan dari peserta jika dia menyetujui untuk turut serta dalam penelitian ini.

Saya mengerti bahwa akan dilakukan wawancara yang lokasinya ditentukan oleh peserta.

Saya mengerti bahwa saya sebaiknya hadir pada saat wawancara.

Saya mengerti bahwa partisipasi bersifat sukarela dan peserta dapat mengundurkan diri setiap saat tanpa sanksi. Penarikan diri dari partisipasi termasuk dalam hal informasi yang telah diberikan sampai di mana bagian informasi yang diberikan sudah menjadi bagian besar dari pembuatan tesis atau untuk publikasi ujian tesis.

Saya memahami bahwa setiap informasi atau opini dari peserta akan dirahasiakan oleh peneliti dan pengawas, dan bila ada hasil yang dipublikasikan atau dilaporkan tidak akan mengidentifikasi peserta dan asosiasi difabel. Saya mengerti bahwa tesis adalah dokumen publik dan akan tersedia melalui Perpustakaan UC.

Saya memahami bahwa semua data yang dikumpulkan (catatan, transkrip, rekaman) untuk penelitian akan disimpan dalam fasilitas yang aman dan dilindungi oleh kunci dan/

atau disimpan dalam bentuk elektronik dan dilindungi oleh sandi dan akan dihancurkan setelah lima tahun.

Saya memahami risiko terkait dengan mengambil bagian dalam penelitian ini dan bagaimana resiko tersebut akan dikelola.

Saya mengerti bahwa saya dapat menerima laporan mengenai penelitian ini dengan menghubungi peneliti di akhir studi.

Saya membenarkan bahwa peserta berumur 18 tahun ke atas, mengalami disabilitas, tinggal di Indonesia dan anggota dari SAPDA (Sentra Advokasi Perempuan, Difabel dan Anak).

Saya memahami bahwa saya bisa menghubungi peneliti, Dhita de LaRoche, phone: +64 22 425 6179, email: fdh14@uclive.ac.nz or supervisor, Associate Professor Ray Kirk, phone: +64 3 364 3108, email: ray.kirk@canterbury.ac.nz and Dr Sarah Lovell, email: sarah.lovell@canterbury.ac.nz untuk info lebih lanjut. Jika saya memiliki keluhan, saya dapat menghubungi Ketua Komite Etik, University of Canterbury, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).

Dengan menandatangani, saya setuju untuk berpartisipasi dalam proyek penelitian ini.

Nama Asosiasi: _____

Tanggal: _____

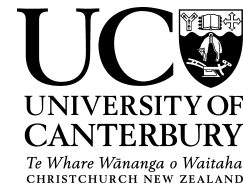
Tanda tangan: _____

Mohon kembalikan formulir persetujuan ini menggunakan amplop berperangko yang telah disediakan ke alamat di bawah ini sebelum ____/____/____

- Kepada: Dhita de LaRoche
SAPDA Yogya
- Alamat: Komplek BNI No. 25 Patangpuluhan
Wirobrajan, Yogyakarta, Indonesia 55252
- Telepon: +62 274 384 066
- Fax: +62 274 384 066
- Email: info@sapdajogja.org

Peneliti,
Dhita de LaRoche

Appendix H: Consent form for participants



Consent Form

School of Health Sciences
Telephone: +64 22 4256179
Email: fdh14@uclive.ac.nz

Health Policy Recommendations for Women with Disabilities in Indonesia

Consent Form for Participants

I have been given a full explanation of this project and have had the opportunity to ask questions.

I understand what is required of me if I agree to take part in the research.

I understand there will be an interview held at a location of my choice.

I understand that my family/caregiver is allowed to accompany me during the interview.

I understand that participation is voluntary and I may withdraw at any time without penalty. Withdrawal of participation will also include the withdrawal of any information I have provided until the point where the contribution is part of a larger body of work and/or submitted for publication of thesis exam.

I understand that any information or opinions I provide will be kept confidential to the researcher and supervisor, and that any published or reported results will not identify the participants and disability association. I understand that a thesis is a public document and will be available through the UC Library.

I understand that all data collected (notes taking, transcripts, audio files) for the study will be kept in locked and secure facilities and/or in password protected electronic form and will be destroyed after five years.

I understand the risks associated with taking part and how they will be managed.

I understand that I am able to receive a report on the findings of the study by contacting the researcher at the conclusion of the project.

Please tick the box provided if you would like to receive a summary of results

YES ☐ NO ☐

If you elect to receive a summary of results, do you want your family and/or caregiver to receive a summary of the results as well?

YES ☐ NO ☐

I understand that I can contact the researcher, Dhita de LaRoche, phone: +64 22 425 6179, email: fdh14@uclive.ac.nz or supervisor, Associate Professor Ray Kirk, phone: +64 3 364 3108, email: ray.kirk@canterbury.ac.nz and Dr Sarah Lovell, email: sarah.lovell@canterbury.ac.nz for further information. If I have any complaints, I can contact the Chair of the University of Canterbury Human Ethics Committee, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).

By signing below, I agree to participate in this research project.

Name: _____

Date: _____

Signature: _____

Please return this consent form using the provided pre-paid postage addressed envelope to the address below before ____/____/____

- To: Dhita de LaRoche
SAPDA Yogya
- Address: Komplek BNI No. 25 Patangpuluhan
Wirobrajan, Yogyakarta, Indonesia 55252
- Phone: +62 274 384 066
- Fax: +62 274 384 066
- Email: info@sapdajogja.org

Researcher,
Dhita de LaRoche

Formulir Persetujuan

School of Health Sciences
Telepon: +64 22 425 6179
Email: fdh14@uclive.ac.nz

Rekomendasi Kebijakan Kesehatan bagi Wanita Difabel di Indonesia

Formulir Persetujuan untuk Peserta

Saya telah diberi penjelasan lengkap mengenai penelitian ini dan diberikan kesempatan untuk mengajukan pertanyaan.

Saya mengerti apa yang dibutuhkan jika menyetujui untuk turut serta dalam penelitian ini.

Saya mengerti bahwa wawancara akan dilakukan di lokasi yang saya tentukan.

Saya mengerti bahwa keluarga/pengasuh saya diperbolehkan untuk hadir pada saat wawancara.

Saya mengerti bahwa partisipasi bersifat sukarela dan saya dapat mengundurkan diri setiap saat tanpa sangsi. Penarikan diri dari partisipasi termasuk dalam hal informasi yang telah saya berikan sampai di mana bagian informasi yang diberikan sudah menjadi bagian besar dari pembuatan tesis atau untuk publikasi ujian tesis.

Saya memahami bahwa setiap informasi atau opini akan dirahasiakan oleh peneliti dan pengawas, dan bila ada hasil yang dipublikasikan atau dilaporkan tidak akan mengidentifikasi saya dan asosiasi difabel. Saya mengerti bahwa tesis adalah dokumen publik dan akan tersedia melalui Perpustakaan UC.

Saya memahami bahwa semua data yang dikumpulkan (catatan, transkrip, rekaman) untuk penelitian akan disimpan dalam fasilitas yang aman dan dilindungi oleh kunci dan/atau disimpan dalam bentuk elektronik dan dilindungi oleh sandi dan akan dihancurkan setelah lima tahun.

Saya memahami risiko terkait dengan mengambil bagian dalam penelitian ini dan bagaimana resiko tersebut akan dikelola.

Saya mengerti bahwa saya dapat menerima laporan mengenai penelitian ini dengan menghubungi peneliti di akhir studi.

Mohon beri tanda pada kotak di bawah ini jika anda bersedia menerima ringkasan hasil penelitian ini.

YA ☐ TIDAK ☐

Jika anda memilih untuk menerima ringkasan hasil penelitian ini, apakah anda menginginkan keluarga/pengasuh anda untuk menerima ringkasan tersebut?

YA ☐ TIDAK ☐

Saya memahami bahwa saya bisa menghubungi peneliti, Dhita de LaRoche, phone: +64 22 425 6179, email: fdh14@uclive.ac.nz or supervisor, Associate Professor Ray Kirk, phone: +64 3 364 3108, email: ray.kirk@canterbury.ac.nz and Dr Sarah Lovell, email: sarah.lovell@canterbury.ac.nz untuk info lebih lanjut. Jika saya memiliki keluhan, saya dapat menghubungi Ketua Komite Etik, University of Canterbury, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).

Dengan menandatangani, saya setuju untuk berpartisipasi dalam proyek penelitian ini.

Nama Asosiasi: _____

Tanggal: _____

Tanda tangan: _____

Mohon kembalikan formulir persetujuan ini menggunakan amplop berperangko yang telah disediakan ke alamat di bawah ini sebelum ____/____/____

- Kepada: Dhita de LaRoche
SAPDA Yogya
- Alamat: Komplek BNI No. 25 Patangpuluhan
Wirobrajan, Yogyakarta, Indonesia 55252
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- Email: info@sapdajogja.org

Peneliti,
Dhita de LaRoche

Appendix I: Semi-structured questions interview

A. English

After I introduce myself and briefly explain the study purpose and objectives, I approach the participants with personal questions to build rapport.

Personal questions:

- What did you do before this interview start? If they were cooking, baby sitting, watching tv, etc will lead to question to:
- What is your favorite thing from that activity? Is that your hobby?
- Do you join a community or neighbourhood activity on the weekend?
- What do you do in your spare time?

Introduction questions

- Please introduce yourself start with age, marital status, type and cause of disability, job status (if you work), location/province where you live now, grow up and experience the disability.
- Could you tell your experience living with disability in Indonesia?
- How is it affecting your life?
- Do you use aid? If the answer Yes or No, could you give the reason why you choose it?
- Could you tell me the affect of your disability condition to the people of your surrounding, e.g.: family, spouse, children, neighbor, etc.?
- How is community treating you with your disability?

- How do you see other WWDs? What is your perception or comment to that condition?

Participant's understanding and experience of disability and health care access

- Could you tell me more of your disability?
Where and how do you learn about your disability?
- How do you think or feel of your current health status? Especially in relation with your disability condition.
- What do you know about rights for disabled? (If they don't know I will briefly explain the current rights and legislation for disabled in Indonesia).
- How do you think of those rights and legislation?
- What do you think could be improve or modify?
- What is your hope and want to be insert to those regulations to accommodate your need based on your experience?
- What do you know of health care services around your area?
- What do you do when you need a health information or suggestion?
Who do you contact as a first gate of information? What was the reason?
- Could you explain the process when accessing a health care services? Is there any payment subsidiary from government for health care or aids?
- How do you decide in choosing a health care services when you need it?
What factors influence your decision?
What do you expect from the services?
How do you feel of the services?

- Could you tell me about your experience of the health worker treatment to you when visited a health center?

How do you feel their attitude toward your disability?

- Could you tell the imprinted experience, either a good and bad experience in receiving a health service?

In your opinion, why is it a good service or bad service?

- According to your experience could you tell the challenges and obstacles when accessing a health center? How about challenges and obstacles from the health workers when accessing a health center for your disability or other needs?

How do you think it could be improve?

- How do you feel about things that influence your attitude toward disabilities?
- Do you think as a woman it is easier to manage the disabilities, compare to men?
If yes, what is the character of women that help it? If no, why do you think?
- Do you think your family and friends understand of your disabilities condition?

Below questions are regarding womanhood situation. I will ask permission to ask this sensitive matter. If participant mind, it will not ask.

- For womanhood health, how do you find trusted information? Could you tell me that experience?

- What do you expect when accessing health care center for sensitive issue?

Do you have imprinted experience, either good or/and bad?

At the end of the interview, there will be a session to allow participant to add information or suggestion outside the questions asked.

B. Bahasa Indonesia

Setelah saya memperkenalkan diri dan menjelaskan secara singkat mengenai maksud dan tujuan riset yang akan dilakukan, saya menanyakan hal-hal pribadi mengenai peserta untuk membangun hubungan baik.

Pertanyaan pribadi:

- Sebelum wawancara sedang melakukan apa? Jika mereka sedang memasak, mengasuh bayi/anak, menonton televisi, dll akan mengarah kepada pertanyaan berikut:
- Apa yang menjadi hal favorit ketika sedang memasak, mengasuh bayi/anak, menonton televisi, dll? Apakah hal itu hobi anda?
- Apakah anda bergabung dengan kegiatan lingkungan atau tetangga pada saat akhir pekan?
- Apa yang anda lakukan ketika mempunyai waktu luang?

Pertanyaan pendahuluan

- Mohon perkenalkan diri anda dimulai dengan umur, status pernikahan, penyebab dan tipe difabel yang dialami, jenis pekerjaan (bila bekerja), lokasi/propinsi tempat tinggal, tumbuh dan mengalami disabilitas.
- Bisa tolong dijelaskan bagaimana pengalaman hidup anda sebagai wanita yang mengalami difabel di Indonesia?
- Bagaimana kedifabelan tersebut mempengaruhi kehidupan anda?

- Apakah anda menggunakan alat penolong? Jika jawabannya Ya atau Tidak, bisakah diberikan penjelasan mengapa anda memilih menggunakan atau tidak menggunakan?
- Bagaimana kedifabelan tersebut mempengaruhi orang-orang di sekitar anda, misalnya keluarga, suami atau istri, anak, tetangga, dll?
- Bagaimana perlakuan komunitas terhadap kedifabelan anda?
- Bagaimana anda melihat kaum wanita difabel lainnya? Apa persepsi atau komentar anda mengenai kondisi mereka?

Pengalaman dan pengetahuan peserta mengenai difabel dan akses ke pelayanan kesehatan

- Bisakah anda ceritakan lebih dalam mengenai kedifabelan anda?
Di mana dan bagaimana anda mempelajari disabilitas?
- Bagaimana keadaan kesehatan anda menurut anda? Terutama yang berhubungan dengan kondisi difabel anda?
- Apa yang anda ketahui mengenai ha-hak untuk difabel? (Jika mereka tidak tahu akan dijelaskan secara singkat mengenai hak dan legislasi untuk difabel di Indonesia yang sudah ada saat ini).
- Menurut anda bagaimana hak dan legislasi tersebut?
- Apa yang bisa diperbaiki atau dimodifikasi?
- Apa harapan dan keinginan anda jika bisa dimasukkan ke dalam regulasi untuk mengakomodasi kebutuhan anda berdasar pengalaman anda sebagai penyandang difabel?

- Apa yang anda ketahui mengenai pelayanan kesehatan di sekitar anda?
- Apa yang anda lakukan ketika anda membutuhkan informasi atau saran kesehatan?
- Siapa yang ada hubungi sebagai kontak pertama informasi? Apa alasannya?
- Apakah dapat dijelaskan proses yang anda alami ketika mengakses pelayanan kesehatan?

Apakah ada subsidi dari pemerintah untuk biaya atau alat bantu?

- Bagaimana anda memutuskan dalam memilih pelayanan kesehatan yang anda butuhkan?

Faktor-faktor apa saja yang mempengaruhi keputusan tersebut?

Apa yang anda harapkan dari pelayanan tersebut?

Apa pendapat anda mengenai pelayanan tersebut?

- Dapatkah anda ceritakan mengenai pengalaman anda ang berhubungan dengan perlakuan pekerja kesehatan terhadap anda ketika mengunjungi pelayanan kesehatan?

Menurut anda bagaimana perlakuan mereka terhadap kaum difabel?

- Dapatkah anda ceritakan pengalaman berkesan, baik pengalaman baik dan buruk ketika menerima pelayanan kesehatan?

Menurut anda, kenapa pelayanan tersebut baik atau buruk?

- Menurut pengalaman anda, apa saja halangan dan tantangan ketika mengakses pelayanan kesehatan?
- Bagaimana dengan halangan dan tantangan dari pekerja kesehatan itu terhadap kebutuhan disabilitas ataupun untuk kebutuhan lain?

- Bagaimana hal itu dapat diperbaiki?
- Menurut anda faktor apa yang mempengaruhi pola pikir dan tindakan anda terhadap kedifabelan anda?
- Apakah sebagai wanita hal itu adalah factor yang memudahkan dalam mengatur kedifabelan anda dibandingkan dengan kaum lelaki?

Jika Ya, karakter apa yang dimiliki oleh wanita yang dapat membantu hal tersebut?

Jika Tidak, apa alasannya?

- Menurut anda apakah keluarga dan teman anda mengerti kondisi difabel anda?

Pertanyaan di bawah ini mengenai keadaan kewanitaan. Saya akan meminta ijin untuk menanyakan pertanyaan sensitif tersebut. Jika peserta keberatan, tidak akan ditanyakan.

- Untuk kesehatan kewanitaan, bagaimana anda mendapatkan informasi terpercaya?
Bisakah anda ceritakan pengalaman mengenai hal ini?
- Apa yang anda harapan ketika mengakses pelayanan kesehatan untuk hal sensitif tersebut?

Bisakah diceritakan pengalaman berkesan mengenai hal ini, yang baik dan buruk?

Pada akhir wawancara akan ada sesi untuk peserta menambahkan informasi atau saran di luar hal yang sudah ditanyakan.